

Psychosocial Interventions in Early Stage Dementia

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Abstract

People with a diagnosis of Alzheimer's Disease or Vascular Dementia who obtained a score of 18 or above on the Mini Mental State Examination and were able to give informed consent were recruited from an Older Adults Service. Group interventions consisting of cognitive rehabilitation, psychoeducation and cognitive-behaviour therapy techniques were provided for people with dementia living by themselves and their partners if applicable. Five people with dementia and four couples completed the intervention. Measures were administered to both people with dementia and their partners at pre-intervention, post-intervention and where possible at follow-up. People with dementia and their partners both completed self-report measures, looking at self-esteem, self-efficacy, anxiety, depression, family functioning and quality of life. Measures were also administered to people with dementia only assessing perceived and actual levels of memory functioning and psychiatric symptoms. In addition, partners were asked to report the number of problematic behaviours displayed by the people with dementia and to describe their own reactions to these. Participants were also asked about their experience of the intervention. There were no significant changes on quantitative measures following the intervention. Partners' reports of the group were positive, but the experience seemed to be valued less by the people with dementia. Reported use of memory strategies did not increase following the group but participants did seem to value the opportunity to meet others in a similar situation and share experiences. The findings suggest that the groups potentially had value to the service for partners of people with dementia, although the intervention was not powerful enough to draw definite conclusions. The intervention was only 8 weeks and people may have benefited

more from a longer intervention. Future research should focus on longer interventions more tailored towards individual needs.

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Some of the material from Chapter 1 has been published as a journal article, the reference of which is below;

Scott, J. and Clare, L. (2003). Do People with Dementia Benefit from Psychological Interventions Offered on a Group Basis? *Clinical Psychology and Psychotherapy*, 10, 186-196.

Chapter One

Introduction

This chapter begins by considering the different types of dementia and proceeds to explore theories in dementia from the perspective of both medical and psychological models. This is followed by an overview of psychosocial interventions and a discussion of some of the difficulties in classifying studies. Finally, the current study, a psychosocial intervention consisting of components of cognitive rehabilitation, psychoeducation and cognitive-behaviour therapy is discussed.

Background to dementia

Dementia is a condition characterised by progressive cognitive impairment. There are other associated difficulties that are not cognitive in nature, such as changes in personality and behaviour, delusions, hallucinations and mood disorders. Reisberg, Ferris, de Leon and Crook (1982) proposed that progression of dementia could be viewed as consisting of seven stages of increasing severity. Although these distinctions may be somewhat artificial it is usually possible to distinguish mild, moderate and severe changes of dementia in clinical practice.

Kay and Bergmann (1980) have estimated the prevalence of mild dementia to be between 6 and 50% and moderate to late-stage dementia between 6 and 15.6% in people aged 65 and over. Kitwood (1997) has suggested that the large variation in prevalence may arise because data has generally been drawn from small samples and a high percentage of people have not wished to be included.

Miller and Morris (1993) also draw attention to the fact that making a diagnosis of dementia is often not clear cut in the early stages, which may account for the much wider variation in the reported prevalence of mild dementia. Miller and Morris (1993) point out that people with lower academic ability may be incorrectly assumed to have dementia. The effects of polypharmacy and mood disorders may also be confused with early-stage dementia (Miller & Morris, 1997) as can delirium. Benign Senescent Forgetfulness (BSF) and Age Associated Memory Impairment (AAMI) are terms that have been used when people have memory problems only and may or may not progress to having more extensive cognitive impairments. Also there is the category of mild cognitive impairment, where impairments are only in one area of cognition, e.g. memory and may or may not progress. Diagnosis of dementia requires there to be problems in more than one area of cognition. Also, depression can sometimes be mistaken for dementia in an older person, although the two do often co-occur and the person who experiences cognitive impairment as a result of depression is at increased risk of developing dementia.

The risk of developing dementia has been found to increase with age. Kay and Bergmann (1980) found prevalence to be 2% in people aged 65 to 69 years and 18% in those over the age of 80 years. Gender differences have also been found. Kay and Bergman (1980) found that males between 65 and 69 years are more likely than females to develop dementia, while females over the age of 80 are more at risk. The explanation for the greater prevalence of males in the younger age band has been suggested by Kay and Bergmann (1980) as being that males in this group are more likely to develop vascular types of dementia.

Types of dementia

Dementia has been classified into cortical types, in which pathology is primarily seen in the main cortex, and sub-cortical types in which atrophy occurs in sub-cortical areas. Alzheimer's Disease (AD), Vascular Dementia (VaD), Lewy Body Dementia (LBD) and Fronto-temporal dementia (FTD) are all cortical types of dementia.

Parkinsons Disease, Pick's Disease and Huntingdon's Disease are examples of sub-cortical types of dementia. Alzheimer's Disease and Vascular Dementia are the most commonly diagnosed types of cortical dementia. It is believed that there are a significant number of mixed cases, for example that there is also vascular degeneration in 20 to 30% of people with Alzheimer's Disease (Gearing et al., 1995) and features of Lewy Body Disease in 15 to 30% of cases of Alzheimer's Disease (Hansen et al., 1990). For the purposes of this review, Alzheimer's Disease, Vascular Dementia, Lewy Body Dementia and Frontotemporal dementia will be considered in more detail.

The types of referrals to memory clinics depend on the clinic, but it has been estimated that 50 to 70% of referrals to a memory clinic can be classified as Alzheimer's Disease (AD) stated by Wilcock, Bucks and Rockwood (1999). AD is generally divided into early, middle and late-stage. In terms of physiology, post mortems have shown that neurofibrillary plaques and tangles are often present in the brains of people with AD. There is also a significant loss of neurons and synaptic connections and acetyltransferase and other neurotransmitters are considerably depleted.

The first symptom of AD is typically problems with episodic memory. Semantic and visuospatial memory are usually impaired to a lesser degree, whereas implicit and procedural memory remain fairly intact at this stage. In short-term memory, there is typically impairment on tasks that require the use of divided attention whereas in long-term memory the main problems are with encoding and retrieval as opposed to storage. Language may also be affected fairly early on, with people typically demonstrating word-finding difficulties and a reduction in verbal output. Although some language problems may arise as a result of perceptual difficulties, this is not sufficient to explain the full extent of the problems experienced (Miller & Morris, 1993). Confabulation (unintentionally producing false information to fill in the 'gaps' in an account) is also common in the early stages.

As the disease progresses difficulties with all the various memory sub-systems manifest themselves. In mid-stage AD, people typically need help in everyday tasks and comprehension and judgement become increasingly impaired. When people are in the late stages of AD, they may not recognise relatives, are dependent on others for all aspects of everyday living and speech is incoherent or language has been lost altogether. Delusions and hallucinations may occur in the early stages of AD but are far more common in the later stages. People with AD and their relatives are often unable to provide a precise date as to when difficulties began. Symptoms of AD vary considerably between individuals and it has been suggested that the term covers a range of conditions.

Vascular dementia (VaD) or multi-infarct dementia has been estimated as being responsible for 10 to 30% of referrals (Wilcock et al., 1999). It is sometimes hard to differentiate it from AD, although there are differences. Typically, there is evidence

of cerebral blood disease, for example multiple infarcts, which could be detected by imaging. In comparison to AD, the beginning of the disease can be more definitely dated and progression tends to be stepwise. There may be other physical symptoms such as headaches or tinnitus in the early stages. People with VaD have higher rates of depression than those with AD and emotional lability also tends to be greater.

Lewy Body Dementia (LBD) has been estimated as accounting for 15 to 25% of people with dementia (Wilcock et al., 1999). Lewy Bodies can be found in the cerebral cortex or other parts of the brain. There are some similarities to AD, but people tend to reach the later stages far more quickly, in some cases between 1 and 5 years (Wilcock et al., 1999). Unlike AD, problems with memory are not necessarily the first symptom. Problems with social functioning can occur in the early stages. Difficulties with attention and visuospatial functioning are more common in early DLB than AD. There are also far greater fluctuations in cognition, with periods of confusion alternating with times people are coherent. Delusions, hallucinations and behaviour difficulties are more frequent in the early stages compared to AD. Visual hallucinations are present in more than 90% of cases of DLB (Wilcock et al., 1999).

Up to 10 percent of referrals are frontotemporal dementia (FTD) as stated by Wilcock et al. (1999), with this condition occurring more in younger people than the previously mentioned types of dementia. This type of dementia is associated with atrophy in the frontal and temporal lobes. Changes in personality and behaviour are likely to be the first symptoms, social disinhibition being a common feature. The extent of memory problems in the early stages varies tremendously.

Past studies have not always differentiated between the various types of cortical dementia but it is probable that most people would have AD or VaD because prevalence rates for these types of dementia are greater than for other types of dementia. As profiles of these types of dementia vary from types of dementia such as LBD or FTD different treatment approaches are also likely to be needed. As AD and VaD together are likely to account for the major proportion of dementia diagnoses, the development of effective psychosocial interventions for this group of people is particularly important. As the intervention in the current study was aimed at people with Alzheimer's Disease and Vascular Dementia, studies which target these types of dementia will be focused on in this review.

Theories of dementia

Although dementia involves neurological change, it is also essential to consider psychosocial factors and how these interact with the neurological component. There has also been a debate over whether dementia is on a continuum to normal ageing or quantitatively different. The threshold theory proposes that dementia and normal ageing are on a continuum, but when a certain level is reached the person can be said to have dementia. Another theory is that neurons are lost at a faster rate in people who have dementia. Both these are continuum theories. The alternative to the continuum view is that there is a qualitative difference between dementia and normal ageing.

According to the medical model, symptoms of dementia are a direct result of brain pathology. Three drugs have been licensed in the U.K. for the use of Alzheimer's Disease, these being Donepezil, Rivastigmine and Galantamine, which are all acetyl-

cholinesterase inhibitors. However, a major difficulty is that these drugs do not benefit all people and there may be adverse side-effects. There are difficulties with using the medical model to explain dementia. Brain pathology is found in people who do not have dementia and the relationship between dementia and degree of atrophy is weak (Kitwood, 1997).

The Person Centred Approach

Kitwood (1997) has put forward the person-centred approach, which proposes that relationships with others and the environment have a major influence on the functioning and behaviour of people with dementia. The idea of ‘malignant social psychology’ was coined by Kitwood (see, for example, Kitwood, 1997). This refers to maladaptive ways of communicating with people with dementia that are likely to heighten cognitive deficits. The psychological approach to dementia care looks at ways of enhancing communication with the person with dementia, and therefore maximising well-being. The concept of ‘excess disability’, when cognitive functioning is further reduced because of negative emotional states that arise as a result of dementia, is well known.

While the possible benefits of drug therapy are recognised, a combination of these and psychological approaches are likely to be the most beneficial approach for people with dementia and their caregivers. Drug therapy does not work for all people with dementia and adverse side effects occur in some cases. Dementia has an effect on a wide variety of aspects of people’s lives and those of their families.

While the primary aim of drug therapy is to improve cognitive functioning, a variety of different areas are targeted through psychological or psychosocial interventions.

While some types of psychosocial interventions are targeted at memory and cognition, others are targeted at a variety of other areas such as acquisition of knowledge and aiming to decrease people's sense of isolation.

A diagnosis of dementia is a difficult situation to cope with for the person concerned and also the person's family. Any support provided to the family may have a positive impact on the person with dementia. Psychosocial interventions are targeted towards families in a variety of ways, for example increasing their understanding and knowledge of dementia, introducing memory strategies at home to help the person with dementia or support to help them cope with the associated difficulties of having a relative who has dementia. Psychosocial interventions can be adapted to meet individual needs and requirements and certain types of intervention are tailored towards different types of dementia.

In summary psychosocial interventions, unlike drug therapy, can be adapted to meet individual needs, target a range of different areas and involve families of people with dementia. Therefore, psychosocial interventions clearly have an important part to play for people with dementia and their families. This review looks at psychosocial interventions that have been carried out with people with dementia and their relatives or carers and considers the evidence for each.

Overview of psychosocial interventions for people with dementia and their carers

A wide range of psychosocial interventions have been carried out with people with dementia. A number of issues need to be taken into account when attempting to review and classify them. Interventions have been carried out with people with dementia themselves, their caregivers or both. Some are carried out on an individual basis, whereas others tend to be implemented in groups. As mentioned previously, dementia has an impact on many areas of a person's life and that of his or her family. Different types of psychosocial interventions target different areas, although an improvement in one area may lead to improvements in others.

Overall, there is a considerable amount of diversity in psychosocial interventions. Different theoretical rationales underlie each type of intervention. For example, the aim of reality orientation is to improve orientation in the current situation whereas support groups aim to offer an opportunity to share ideas, decrease a sense of isolation and improve emotional well-being. However, it is worth noting that the theoretical rationale for the interventions reported is not always clear (Bourgeois, Schulz & Burgio, 1996). In addition, there is a degree of overlap between different types of interventions. Cognitive rehabilitation and cognitive training are terms often used interchangeably in the literature. Clare, Woods, Moniz-Cook, Orrell and Spector (2004) define the difference between the two types of interventions; they state that cognitive training may be carried out on an individual basis or in groups and usually involves practising standard tasks which are designed to target particular functions such as memory or attention, with the aim that improvements will generalise to other areas, while the aim of cognitive rehabilitation, which is carried

out on an individual basis, is to improve level of functioning in an everyday context as opposed to improving functioning on certain tasks. Psychoeducational groups and support groups often have similar aims, namely to increase understanding of dementia and related aspects and provide participants with the opportunity of sharing ideas and experiences and providing each other with support.

The issue of similarities and differences between different types of intervention presents difficulties when reviewing the literature. In addition, the same name can be used to describe a number of different techniques. Holden and Woods (1982) discussed the many differences between 21 reality orientation studies they looked at. The fact that interventions with the same name can vary widely is not helped by the fact that they are often not described in sufficient detail. In addition, some interventions include a number of different components (e.g. Brodaty, Gresham & Luscombe, 1997; Mittelman, Ferris, Schulman, Steinberg & Levin, 1996). Although it has been suggested that caregivers are more likely to benefit from interventions that consist of multiple components (Brodaty et al., 1997), it is difficult to draw conclusions about the efficacy of each.

Some interventions are targeted at people in certain stages of dementia. For example, cognitive therapy requires a high degree of verbalisation and therefore would be potentially applicable only for people in the early stages of dementia, whereas validation therapy is aimed at people in the later stages of dementia. For other interventions, it is not clear what types of participants are likely to benefit most. For example, there is some debate over the type of participants reality orientation is most useful for. Brook, Degun and Mather (1975) have reported that the most positive outcomes are associated with people in the early stages of

dementia, Holden and Woods (1982) suggested it may be best carried out with people who have more advanced dementia and Hanley, McGuire and Boyd (1981) found that outcomes for RO were not related to stage of dementia. Brodaty et al. (1997) comment that an intervention will be more beneficial if carried out with people in the early stages of dementia. However, it is worth taking into account the observation of Powell-Proctor and Miller (1982) that there seems to be a belief that people with a similar stage of dementia will automatically have similar needs and will benefit from the same type of intervention, which is not necessarily the case. Powell-Proctor and Miller (1982) point out that adaptation to individual requirements is likely to result in more successful outcomes and Brodaty, Green and Koschera (2003) state in a meta-analysis of psychosocial interventions for caregivers of people with dementia that interventions that are adapted to caregivers' needs are likely to be more successful. Therefore, stage of dementia is likely to be just one of a number of factors that should be taken into account. Ishizaki et al. (2000) comment that there are various sub-types of Alzheimer's Disease that vary in terms of symptoms and progression, which may be important when planning an intervention.

Where interventions are targeted at caregivers, it may also be important to select those with similar needs, although there is some debate over this. Chiverton and Caine (1989) highlight the importance of ensuring that participants have similar needs, whereas Glosser and Wexler (1985) suggest that it is more useful to include participants at different stages in the caregiving process. Pusey and Richards (2001) point out that the fact that caregivers participating in an intervention are often a heterogeneous group makes it difficult to evaluate studies effectively. Along similar lines to the comment by Powell-Proctor and Miller (1982) about people with dementia outlined above, Pusey and Richards (2001) state that even when caregivers

are caring for people with a similar stage of dementia, there will still be a great deal of variation between them.

In conclusion, the factors that make it difficult to classify psychosocial interventions include inadequately described procedures, the overlap between interventions and the fact that some interventions include a range of components. This is confounded by the fact that many studies do not have a clear theoretical rationale and that it is not always apparent which type of participants, in terms of stage of dementia, an intervention is aimed at. Clearly, what are required are psychosocial interventions that are theoretically derived and empirically supported. The review begins by considering the more traditional approaches of reminiscence therapy, reality orientation and validation therapy, before considering cognitive rehabilitation and cognitive stimulation, which have been more recently introduced with people with dementia. Psychoeducation and support groups are then discussed before moving on to psychotherapy, counselling, behavioural and cognitive-behavioural approaches. This review primarily considers studies with people with early stage dementia and their carers, as the study to be reported here was aimed at this group of people and as previously mentioned focuses on interventions for people with Alzheimer's Disease or Vascular Dementia. Evidence for the efficacy for each type of intervention is considered, which led to the planning of session content in the current study.

Reminiscence Therapy

Reminiscence therapy (RT) is usually carried out in groups although it has been noted that it may be more useful on an individual basis for people who feel more comfortable with the latter or who have more advanced impairment (Ashton, 1993).

RT involves the discussion of themes and events from the past. The aims of RT are to provide social interaction and enjoyment (Woods, 1996), but there also seems to be an assumption that it will have a positive effect on functioning. However, although RT has been widely used there is a lack of evidence available for any effect on cognition and behaviour. This may be partly due to the lack of high quality studies available, which is highlighted in a systematic review by Spector, Orrell, Davies and Woods (2004^a), in which only two studies were identified and only one was suitable for meta-analysis (Baines, Saxby & Ehlert, 1987). This was a cross-over design of RT and reality orientation, but the review focused on the RT component. There were no significant results for cognition and behaviour, although outcomes for the latter were encouraging. However, the reverse was found in a study by Goldwasser, Auerbach and Harkins (1987), the other study found in the above review. Although results again were not significant, cognition improved more than behaviour. It is also worth mentioning that although levels of depression initially significantly decreased they rose again at follow-up. Due to lack of evidence available for the efficacy of RT, it was decided not to consider incorporating it into the current intervention. In addition, including family members in an intervention is considered important and this had not been done with any of the identified RT interventions.

Reality Orientation

As mentioned previously, there is some debate over who may benefit most from reality orientation (RO), although it is more commonly carried out with people with more advanced dementia in residential care or hospital settings (see, for example, Hanley, McGuire & Boyd, 1981). RO aims to improve orientation to time and place

in the here-and-now situation and uses instruments such as boards displaying the day, month, season and weather conditions. The main aim of RO is to improve cognition, although it has been pointed out that this may not extend beyond information covered in the intervention or to changes in behaviour (Woods, 1996). This is supported by some studies that have found significant improvements in cognitive outcomes but not behaviour (Hanley et al., 1981), but others have found improvements on behavioural outcomes (Baines et al., 1987). However, it is worth noting in the latter study that there were significant changes on only one of two behavioural measures used.

Cognitive stimulation has been developed following on from RO. Some of the principles of RO are used in cognitive stimulation, which involves practice on a range of tasks aimed at enhancing various areas of cognitive functioning. It has been used on a one to one basis, in couples and also in groups. Breuil et al. (1994) reported results from a randomised controlled trial of a cognitive stimulation group for people with mild to moderate dementia, which took place for 10 weeks. Findings showed significant improvements in cognitive test scores but not activities of daily living. Spector et al. (2003) described a randomised controlled trial in which people with dementia were assigned to cognitive stimulation programme or a control group. The intervention group scored significantly better than the control group at follow up on measures of cognition and quality of life.

There are several important issues to consider in discussing the interpretation of findings from RO studies. First is the issue of whether RO can have adverse effects. This is particularly important in view of the fact that RO has been criticised for being too confrontational, although arguably this is due to a misunderstanding of the concept underlying RO rather than the technique itself. One study did find that

participants became upset following RO (Dietch, Hewett & Jones, 1989). However, this intervention involved only three participants and studies in general have not demonstrated adverse effects. Second is the issue of therapist attention effects. A number of studies have introduced a social group as a comparison to the RO intervention in order to control for this factor. In some cases outcomes for the RO group have been found to be superior to a social group (Woods, 1979) whereas in others outcomes have not varied (Gerber et al., 1991; Wallis, Baldwin & Bigginbotham, 1983). A third important issue is that functioning of people with dementia would be expected to decline over time, which has implications when assessing the effectiveness of an intervention. Ishizaki et al. (2000) described an intervention with an RO component that was considered effective because scores on cognitive, mental and behavioural measures remained at the same level overall. However, it is worth pointing out that this intervention took place for a period of three months only and dramatic changes in abilities may not be expected in this time. A final issue to consider is whether any positive effects will remain at follow-up. Woods (1996) states that further input is required after any intervention or effects will be lost. This is supported by an RO intervention described by Gerber et al. (1991) in which positive outcomes were lost at follow-up, although Reeve and Ivison (1985) reported a study in which effects were maintained when the intervention had ceased. However, there were methodological problems with the latter study, as it appeared that participants were actually receiving some form of further input when the intervention was meant to have ended.

Overall, although there are indications that RO may be of benefit, problems with methodology and quality of studies makes it difficult to draw firm conclusions. The lack of high quality studies is highlighted in a systematic review by Spector, Orrell,

Davies and Woods (2004^b). Only six studies that met the criteria were identified. Cognitive and behavioural changes were significant, but it is important to note that results for the former were heavily weighted by a cognitive stimulation study (Breuil et al., 1994) and only half the studies used behavioural measures. Of course, there may be other important changes that are not reflected in cognitive or behavioural measures. For example, Ishizaki et al. (2000) found that participants began to communicate more and built up relationships with each other.

In summary, although there is more evidence available for the efficacy of RO than RT, it is still hard to draw any firm conclusions. In addition, it has been more commonly used with people with advanced dementia whereas the planned intervention for the present study was for people with mild dementia. Therefore, it was decided RO was not appropriate for the current intervention.

Validation therapy

Validation therapy (VT) was initially developed by Feil (see, for example, Feil, 1992) as an alternative to RO, which was felt to be too confrontational. VT can be carried out both individually and in groups. It rests on the assumption that the feelings people are experiencing should be listened to and not corrected even if the facts are not correct. Another important concept is the idea that people will return to issues in their past in order to deal with them at a psychological level. De Klerk-Rubin (1995) states that the aims of validation groups are 'to stimulate energy and interaction both verbally and non-verbally, and increase each group member's sense of identity by calling up social roles from the past'. The content of group sessions may include elements from other types of intervention, such as reminiscence therapy

and life review. There is a standard format to VT groups, including discussion, singing, and the assignment of roles such as 'welcomer' or 'hostess' (Morton & Bleathman, 1991).

There is a lack of evidence available for VT as demonstrated in a systematic review by Neal and Briggs (2004). Only three randomised controlled trials were identified and it was not possible to combine the results from the studies because of the interventions having different time periods, varying control treatments or different outcome measures. Although one study showed a positive effect of validation behaviour with regards to behaviour and another depression, Neal and Briggs (2004) pointed out that the small number of studies and the fact that meta-analysis could not be carried out meant it was not possible to make any definite conclusions about the effectiveness of validation therapy. Other problems that were also identified by the authors were that in some cases it was not clear whether participants actually had dementia, outcome measures only considered cognitive and behavioural aspects (as opposed to any effects on caregivers) and the lack of definition of the interventions making it difficult to ascertain exactly what they constituted. The lack of evidence for VT and the fact it is aimed at people in the later stages of dementia meant it was not considered as a possible component in the current study.

Cognitive training and cognitive rehabilitation

A systematic review of cognitive rehabilitation and cognitive training for people with early stage Alzheimer's Disease was carried out by Clare et al. (2004), with the two types of intervention being considered separately. Six studies that met the criteria for

cognitive training were identified, but results were not significant although a slight but non-significant improvement in cognitive functioning was noted. Although the authors conclude that there is no firm evidence for this intervention, they also point out that this must be regarded with caution due to the small number of randomised controlled trials. There were no randomised controlled trials identified involving an individualised cognitive rehabilitation approach. In a review of cognitive rehabilitation, De Vreese, Neri, Fioravanti, Belloi and Zanetti (2001) identified three types of techniques used: focusing on implicit memory, targeting explicit memory with support at encoding and retrieval, or implementing memory aids. Memory aids can be internal, as in mnemonics, or external, as in a calendar. Obviously even external aids require use of internal strategies. For example, somebody will need to remember to look at a calendar. Other techniques that may be used in cognitive training or rehabilitation are errorless learning, expanding rehearsal and vanishing cues. Errorless learning is based on the principle that if people with dementia give an incorrect response initially they are likely to recall this information in the future, even if subsequently provided with the correct response. Therefore, only correct responses should be encouraged. For example, if a person with dementia is learning the name of somebody, he or she should be encouraged only to provide the correct response rather than to guess. Expanding rehearsal and vanishing cues are techniques that can be used in conjunction with errorless learning. In expanding rehearsal, participants are presented with a stimulus within specified time intervals. When they are able to recall the information correctly, these intervals are gradually increased. For this review, studies that have involved cognitive training will be considered initially before moving on to cognitive rehabilitation.

Zanetti et al. (1997) described a study in which participants with early to moderate Alzheimer's Disease were trained in daily living activities. Significant improvements were found not only for these tasks but others that training had not been provided in. In another study by Zanetti et al. (2001), participants with early to middle-stage Alzheimer's Disease were given training in activities such as using the telephone, dressing, reading and writing. Results were significant in favour of the intervention, with the treatment group carrying out the tasks more quickly. The control group increased in time taken, although this did not reach significance. However, one difficulty with interpreting the results, as pointed out by the authors, is that the intervention and control group differed significantly prior to the intervention on a task of forward digit-span.

In an intervention consisting of cognitive training described by Quayhagen and Quayhagen (1989), people with dementia were trained by their families for six hours each week by using memory exercises and problem solving techniques. The fact that the cognitive abilities and behavioural functioning of the treatment group remained stable but that of the control group became significantly worse was taken as evidence that the intervention was beneficial. In addition, it was found that the well-being of caregivers remained the same in the intervention group, but became significantly worse for controls. However, although caregivers generally gave positive reports about the intervention, they did not tend to feel that there had been a beneficial effect on cognition and behaviour of the people with dementia. As Quayhagen and Quayhagen (1989) point out, there are other possible reasons why scores obtained from the control group became worse, such as relationship difficulties, or the possibility that people with dementia may have been functioning at a lower cognitive level initially.

In a study described by Camp, Foss, O'Hanlan and Stevens (1996) four participants with Alzheimer's Disease were taught to use a calendar, using errorless learning techniques. This met with reasonable success, although results were less encouraging for a second component of the intervention, which was a task designed to use prospective memory. Hofmann, Hock, Kühler and Müller-Span (1996) discussed a study that involved the replication of everyday situations, such as shopping, on a computer screen. Ten participants with mild to moderate Alzheimer's Disease were asked to go through the tasks on the screen. It was found that participants could carry out the tasks more independently, quickly and with fewer errors after three weeks. The authors noted that participants who were less efficient at the task initially made greater gains. However, one difficulty with the study is the issue of how far the results can be generalised to real life. A study by Arkin (1998) involved participants listening to tapes that contained information they had difficulty in remembering, which had been especially compiled for each of them. Findings showed that participants were able to recall a large number of the facts on the tapes. In another study by Arkin (2001), participants were taught personally-relevant information, although little detail was supplied about the actual procedure used. The fact that the scores of the Mini Mental State Examination fell significantly for participants in the control condition, but not the treatment group, was taken as an indication that the intervention was successful.

In a study described by Hoerster, Hickey and Bourgeois (2001), four participants with dementia were provided with memory books, which contained pictures and information relevant to each of them. Following training in how to use the memory books, improvements in conversational ability were noted. Use of mnemonics is a

technique in which visual or verbal associations are made to aid recall. Bäckman, Josephsson, Herlitz, Stigsdotter and Viitanen (1991) described a study that made use of this technique. Seven people with Alzheimer's Disease and one with multi-infarct dementia participated in the intervention. Participants were asked to remember the names of people in photographs by using a mnemonic strategy. The ability of each participant was assessed initially and this determined the number of photographs presented. However, results were not promising, with only one participant being able to remember names for a longer period of time after the intervention. The authors concluded that mnemonics do not work well because they make use of abilities that are extremely compromised by dementia. In addition, it was noted that participants found trying to use mnemonics prevented them from using their normal technique of rehearsing the information.

One cognitive training intervention for people with early to middle-stage dementia (Koltai, Welsh-Bohmer & Schmechel, 2001) drew from a range of techniques for each participant, including spaced retrieval, a face name recall technique and use of external memory aids. Individual and group conditions was combined when analysing the results. There was no difference between the treatment group and controls in cognition and mood, although positive trends were noted. A retrospective analysis was carried out which showed that participants who had most awareness of their memory difficulties performed significantly better. Problems with the study must be taken into account, which includes the small numbers of participants and the fact that the intervention varied for each of them.

Moving on to cognitive rehabilitation, Clare, Wilson, Breen and Hodges (1999) and Clare, Wilson, Carter, Hodges and Adams (2001) described a study with a 74-year

old with early-stage Alzheimer's Disease. The participant was taught the names of 11 people at a group he attended by using photographs of each of them. Errorless learning principles were adopted. Training took place at weekly or monthly intervals over a two-year period and the participant continued to be able to recall a significantly greater number of the names than he had prior to the intervention, despite a decline in some areas of cognitive functioning and a significant reduction in recall of names for which no training had been provided. Errorless learning principles were used in another study described by Clare, Wilson, Carter, Breen, Gosses and Hodges (2000). Individualised interventions for six people with dementia, including the participant in the above study, were described. Four of the participants were taught names or information relevant to themselves and the remaining two were given training in the use of memory aids. Significant results were found in favour of the intervention for five of the participants. Results for the other participant were not significant.

Josephsson et al. (1993) described an intervention in which four participants with moderate to advanced dementia were each given training in a task of daily living. A task was selected for each participant on the basis that he or he was experiencing difficulty in this area. The authors reported that three of the participants demonstrated gains in process skills, although details as to the exact nature of these were not supplied.

Conversational ability is usually compromised from the early stages of dementia. Some interventions have implemented memory aids that have specifically targeted this. Bourgeois (1990) described an intervention in which three people with Alzheimer's Disease were trained by their partners to use prosthetic memory aids to

help with conversation. Again, results were positive with participants being able to use the memory aid successfully, resulting in improvements in conversation.

One important question is whether any effects are maintained once input has ceased in cognitive training or cognitive rehabilitation. Positive changes were maintained following the previously described cognitive rehabilitation interventions by Clare et al. (1999) and Clare et al. (2000), with a number of follow-up assessments being carried out, for up to 9 months after the intervention and there was a follow up for a second and third year after the end of the intervention with one participant, which demonstrated long-term maintenance of gains (Clare et al., 2001). With respect to the cognitive training interventions described by Bäckman et al. (1991) and Camp et al. (1996), Bäckman et al. (1991) found that the participant who was able to make use of the taught mnemonic strategy was still applying the technique at a follow-up session one month later, while Camp et al. (1996) noted that participants still continued to use a calendar after their intervention. Another important consideration is whether gains generalise. In the cognitive training interventions by Hofmann et al. (1996) and Zanetti et al. (1997) the former found this not to be the case but the latter found that the results generalised, with improvements on untrained as well as trained items. Finally, it is important to know whether participants value the intervention. A criticism of memory training is that people may find the experience upsetting because it highlights their deficits. De Vreese et al. (2001) point out that the effect on mood has often not been addressed in cognitive rehabilitation studies. However, there are exceptions to this, for example Clare et al. (2000). Some studies have considered how participants viewed the intervention, although this has not been looked at in depth. For example, with respect to cognitive training, Hofmann et al. (1996) found that participants had a sense of accomplishment after carrying out the

intervention and Arkin (1998) goes as far as to argue that that participation has a positive effect even if any changes are not maintained. De Vreese et al. (2001) point out that even small improvements in cognitive ability may be important to participants.

Evidence for the efficacy of cognitive training and cognitive rehabilitation is limited; however this is the case for psychosocial interventions for people with dementia in general and there is more evidence to support these types of interventions than others. Some interventions have met with success, although the point that any gains may not be generalised to situations outside the intervention is an important consideration. Individually targeted rehabilitation should be considered as opposed to standardised training. Other important points to consider are the participant's affective state and sense of well-being. It is important to introduce measures that assess these areas.

Psychoeducation

Psychoeducational programmes have generally been run for carers of people with dementia (e.g. Chiverton & Caine, 1989) but have also been described for people with dementia themselves (e.g. Thrower, 1998). They generally involve the provision of information about dementia and related aspects, with some extending to include a wide variety of topics, for example, legal issues (e.g. Glosser & Wexler, 1985). They have generally been conducted on a group basis (e.g. Chiverton & Caine, 1989; Glosser & Wexler, 1985). As mentioned previously, the distinction between psychoeducation and cognitive rehabilitation interventions is not always clear, but the former are usually carried out with carers and tend to cover a range of

topics with the aim of increasing understanding of the person with dementia and suggesting useful coping strategies. In this section, psychoeducational studies with caregivers will be considered initially. Interventions for people with dementia and for both people with dementia and their caregivers are then considered.

Chiverton and Caine (1989) described a psychoeducational group for husbands and wives of people with Alzheimer's Disease, which covered information about dementia and coping strategies. The 'Health Specific Family Coping Index' (HSFCI), which is a measure that addresses coping skills, was used to assess change. The main improvement was in knowledge but there were also significant changes in areas of therapeutic and emotional competence. However, it is worth noting that the HSFCI covers six other areas, none of which showed a significant change. Glosser and Wexler (1985) also described a group for caregivers. The intervention lasted for 8 weeks and information about Alzheimer's Disease, coping skills and legal and financial issues were discussed. A major problem with the study was that formal outcome measures were not used, although reports from participants were encouraging. Glosser and Wexler (1985) found that eight weeks was not a sufficient period of time to meet the needs of participants, with some of the caregivers subsequently forming their own group. These findings are not surprising given the complex and ever-changing needs of people with dementia and their caregivers. However, the fact that participants formed their own group is a positive outcome, as it implies that they probably gained benefits from the group experience.

Participant reports are not necessarily supported by results from objective measures, as demonstrated in a psychoeducational programme for caregivers described by Brodaty, Roberts and Peters (1994). The six sessions included information about

dementia, problems that may arise and coping skills. Despite the fact that 62% of participants stated that the group had been beneficial, there were no significant changes in objective measures that looked at burden, life satisfaction and emotion. This implies that either participants liked the course despite the fact there was no improvement or the measures were not able to detect changes.

Magni, Zanetti, Bianchetti, Binetti and Trabucchi (1995) looked at a study that explored whether outcomes of a psychoeducational group for caregivers were influenced by the characteristics of people with dementia and their caregivers. The intervention lasted for eight weeks and covered information about dementia, difficulties arising from the condition and help available. Findings showed that stress was reduced most for caregivers of people with moderate to severe dementia. However, as the authors pointed out, the intervention was aimed at this group of people and may therefore have been less useful for caregivers of people with mild dementia. Also, participants with more previous education were found to gain more knowledge as a result of the programme. Finally, it was shown that caregivers of people with mild dementia increased their knowledge more than those with middle or late stage dementia. However, the authors pointed out that the questions assessing knowledge were biased towards mild dementia and therefore it is difficult to draw conclusions from this finding. Also, this observation does not take into account that caregivers of people in particular stages of dementia are not a homogenous group and there may be important differences between them that would result in a certain type of intervention being successful for some but not others. The fact that the questionnaire was tailored towards mild dementia but the intervention was aimed at caregivers of people with more advanced dementia is an obvious problem. Another difficulty with the study is that there was a low response rate to the invitation to

attend the programme and a high drop-out rate. Out of 378 people approached initially, only twenty-two completed all parts of the intervention, and there may have been important differences between people that took part and those who chose not to.

Haupt, Karger and Jänner (2000) discussed a psychoeducational programme for caregivers that looked at whether there were any positive effects on the people with dementia. It consisted of a weekly group that lasted for three months and covered information about dementia, cognitive-behavioural techniques and advice about agencies. Measures were not administered to the caregivers, but the people with dementia were found to significantly improve in anxiety and agitation, and this was interpreted as being a direct result of the intervention. Although this is promising, it is important to note that these were just two of the six sub-scales in the measure used (the BEHAVE-AD) and there was no global significant change. However, the authors do point out that as there were few difficulties in the other areas addressed there was little scope for change. This implies that the BEHAVE-AD may not have been the most suitable measure to use with participants.

Some interventions for caregivers have included a range of components including psychoeducation (e.g. Brodaty et al., 1997, Mittelman et al., 1993, 1995, 1996). Brodaty et al. (1997) described a 10-day residential programme for people with dementia and their caregivers that included information about dementia and related aspects for caregivers and activities for the people with dementia. Caregivers who had taken part in the programme were compared with those who had not. It was found that the people with dementia stayed at home for a significantly longer period of time when their caregivers had been in the programme. In addition, there was a positive trend for survival rate for people with dementia when caregivers had

received the intervention. Although these results appear promising, there are a number of difficulties with the study. For example, it is not clear how confidently findings on the outcome measures used can be attributed to such a time-limited intervention. It is likely that a number of other factors were at play. Also, the authors point out the caregivers who chose to participate may have been those who wanted their relatives to remain at home. Mittelman et al. (1993), Mittelman et al. (1995) and Mittelman et al. (1996) describe another study that consisted of a range of components. Although the intervention was described as consisting of counselling and support groups, it was also stated that psychoeducation was a core element. Promising results were found in outcomes of caregiver depression and institutionalisation of the people with dementia. One major difficulty with studies that incorporate a range of techniques is that it is not possible to assess the efficacy of the components, as pointed out by Brodaty et al. (1997) in relation to their study.

There are a number of important issues that need to be considered. One such issue is that of the characteristics of caregivers. Chiverton and Caine (1989) suggest that it is important to select groups of caregivers that are fairly homogenous. Caregivers in their study were at various stages of the process and it was consequently found that some had adapted more to the situation than others. It was noted that one participant whose relative had only recently received a diagnosis of dementia became particularly upset. Interestingly, this view is contradicted by findings from the study by Glosser and Wexler (1985) where it was deemed useful to have caregivers at different stages in the process. It was reported that caregivers whose relatives were in earlier stages of dementia found it useful to learn what may occur in the later stages. How helpful this is may depend on the purpose of the group. For example, it may be helpful for a group to consist of caregivers of people in similar stages of

dementia if emotional support is a principle aim. Another important point is that some caregivers may be more likely to benefit than others. As demonstrated by Magni et al. (1995), the characteristics of caregivers and people with dementia may influence outcomes. A second important issue is whether there is a relationship between previous level of education and outcome. Brodaty et al. (1994) found that this was not the case, but Magni et al. (1995) found superior outcomes to be associated with higher levels of education. Third, it is important to consider the relationship between quantitative and qualitative findings. In line with other types of intervention, qualitative findings have often been encouraging even when there have been no significant changes on formal outcome measures (e.g. Brodaty et al., 1994; Thrower, 1998). Fourth, as is the case with interventions for people with dementia and their caregivers in general, there are a number of methodological problems with studies, for example limited statistical power due to small numbers (e.g. Brodaty et al., 1994) or lack of formal outcome measures (e.g. Glosser & Wexler, 1985). Finally, it is important to acknowledge that group interventions do have limitations. Glosser and Wexler (1985) pointed out that although many topics worked well, others would have been best implemented on an individual or family basis.

As mentioned previously, there have been far fewer psychoeducational programmes carried out with people with dementia themselves. However, one example is a group described by Thrower (1998). Each meeting took place over six hours and a broad range of discussion topics, including presentations by guest speakers, and activities was included. Reports by relatives were encouraging, but these were not supported by results from objective measures addressing mood and self-esteem. Thrower (1998) initially described an eight-week group with each session lasting for an hour and a half. Information about memory and coping techniques were covered.

However, it was found that this was an insufficient amount of time to provide the degree of support required by participants and was therefore extended. Thrower (1998) goes on to point out that even the extended type of programme she described should be considered as just part of the help provided. As negative mood states such as anxiety and depression can lead to excess disability in people with dementia, adequate attention needs to be paid to emotional issues. Thrower's study set aside specific sessions to explore such issues. The initial six sessions covered information about memory whereas the final two were dedicated to how negative states can affect memory and relaxation techniques. This seems to be a logical format, in that participants are more likely to feel comfortable discussing emotional issues when they have had chance to become familiar with other group members. One potential difficulty with group interventions is that people with dementia may find it harder to process information in a group than they would on a one-to-one basis (Alberoni, Baddeley, Della Sala, Logie & Spinnler, 1992) or do not feel comfortable with the idea of being in a group situation.

Other interventions have been aimed at both people with dementia and their caregivers, for example an intervention described by Moniz-Cook et al. (1998), which lasted between six and twelve hours. This included a counselling component that had an emphasis on psychoeducation. Results were found in favour of the intervention for well-being of people with dementia and their caregivers and memory scores obtained by the former group at eighteen month follow-up. Significantly fewer people with dementia went into institutional care in the intervention group. The authors state that it is difficult to determine the relative efficacy of each component in this multi-component intervention. It may be useful to explore the effects of the separate components in future studies, although it is worth considering

that any positive results may be due to the cumulative effect of the different techniques. Another intervention for both people with dementia and their caregivers was described by Ostwald, Hepburn, Caron, Burns and Mantell (1999). While caregivers attended a psychoeducational programme the people with dementia attended another group that ran simultaneously. The psychoeducational programme explored how the behaviour and feelings of caregivers were affected by the progressive decline of the cognitive abilities of the people with dementia over seven sessions. While the level of carer burden increased significantly initially, it had significantly reduced at a five-month follow-up. This highlights the importance of carrying out follow-up sessions to detect delayed changes. In psychoeducational programmes, there may be a delay before any positive effects become apparent, because it may take a while to take new information on board. However, there may be different patterns for other outcomes. For example, in the same study, there were no significant changes in depression, or in the levels of difficult behaviours displayed by the people with dementia and caregivers' reactions to these. The cognitive functioning of the people with dementia decreased for both the intervention and control group, but this would be expected due to the progressive nature of the condition.

An important assumption behind psychoeducational programmes is that they will provide emotional support. This may be derived from the sharing of experiences with others in a similar situation, increased understanding about dementia and related behaviours or the utilisation of coping strategies that have been discussed, which may lead to improved management of problematic areas. There are a number of important issues to consider with regards to psychoeducational interventions. Despite the fact there are some difficulties with the existing studies in terms of

methodology, some benefits have been demonstrated for both the person with dementia and the caregiver. Some studies have demonstrated positive changes on objective measures in addition to encouraging qualitative findings while others have only demonstrated changes in the latter. One possible reason for encouraging qualitative findings is that as a result of social constraints participants may feel obliged to make positive statements about the facilitation. Although limitations to group interventions are acknowledged, there do also seem to be benefits, in terms of participants being able to share information and provide support to each other.

Although problems with methodology in psychoeducational studies for people with dementia are recognised, there is more evidence available for the efficacy of this type of intervention than other types and it was therefore included as a component in the current study.

Support groups

Support groups have been described by Yale (1995) as consisting of ‘a discussion format to offer a combination of education, emotional and practical assistance’. Yale (1995) argues that ‘support groups can provide a therapeutic environment for the participants in which changes in life-style can be discussed, information and reassurance about symptoms offered and community resources to assist with problem solving identified’. Support groups were previously targeted at caregivers (e.g. Zarit et al., 1987) but are now increasingly being offered to people with dementia or both people with dementia and their caregivers (e.g. Aronson, Levin & Lipkowitz, 1984; Hawkins & Eagger, 1999; Sainsbury et al., 1996). This section considers support

groups for caregivers, people with dementia and those for both people with dementia and their caregivers in turn.

Zarit et al. (1987) compared support groups and counselling for caregivers of people with dementia. There was also a further group of participants who constituted a wait list control group. There were no significant differences between participants in the three conditions on objective measures, although participants gave positive reports about both types of intervention. Mittelman et al. (1993), Mittelman et al. (1995) and Mittelman et al. (1996) described an intervention for caregivers that consisted of support groups and counselling. Although significant outcomes were found for depression and nursing home admission for people with dementia, it is not possible to tease out the relative efficacy of the two types of technique. Another difficulty is how confidently one intervention can affect nursing home admission, which presumably is likely to be dependent on a number of factors. Thompson and Briggs (1998) highlighted the lack of evidence available in a systematic review of interventions comprising a supportive element for caregivers. However, it was not possible to carry out a meta-analysis because of the poor quality of the studies and wide variation in methodology and outcome measures. Brodaty et al. (2003) carried out a meta-analytical review of controlled trials involving caregivers and identified 30 studies, that consisted of 34 interventions in total. The authors concluded that the quality of interventions has improved over 17 years and some interventions can have positive effects, for example reducing symptoms of morbidity in caregivers and resulting in the person with dementia being able to remain at home for longer. In addition, caregivers tend to view the intervention positively. The authors pointed out that the most successful interventions are likely to be those that involve both the caregiver and the person with dementia and that are individually tailored to people's

needs and that future research should focus on helping clinicians develop their ability to select an intervention that would be suitable for each individual case. As is the case with other reviews, the authors pointed out there are a limited number of studies and there are problems relating to methodology for those studies that there are.

There have also been a number of support groups for people with dementia themselves. Hawkins and Eagger (1999) described an open support group in which a wide range of subjects was covered including responses to diagnosis, emotions and more practical issues. The authors argued that evaluation using objective measures would be inappropriate due to the progressive nature of dementia. Anecdotally, however, there were positive comments from carers and day hospital staff with improvements noted in participants' abilities for limited periods of time following the group sessions. Another support group was described by Sainsbury et al. (1996). There were four participants with early stage dementia and another whose problems were functional in nature. Self-rating scales of happiness, confidence, affect and feelings about social situations did not generally show any dramatic changes. However, the authors suggested that the intervention might have enabled participants' scores on measures to remain stable when they may otherwise not have done, although the lack of a control group presents difficulties in drawing this conclusion. Facilitators also made positive comments about the group, although subjective reports are open to bias. Another intervention described by Pratt, Clare and Aggarwal (2005) was a user-led support group for people with dementia that was valued by its members.

Other interventions providing support have been aimed at both people with dementia and their caregivers. Aronson et al. (1984) described weekly groups run

simultaneously but separately for people with mid-stage to late-stage dementia and their carers. While the people with dementia were provided the opportunity to participate in activities, the carers' group explored the effect that dementia had had on their lives and ways of adapting to these changes were addressed. Although formal outcome measures were not used, the authors pointed out that the high attendance rate and the fact that participants chose to visit each other between sessions was a strong indicator that the group was valued. The authors also stated that carers had reported positive changes in the people with dementia in everyday life.

Other types of intervention providing support for people with dementia and their caregivers have been described. In a study by O'Connor, Politt, Brook, Reiss and Roth (1991) people with dementia and their caregivers were randomly assigned to an intervention or control condition. The intervention group was provided with a wide range of practical support, including home help, advice on financial benefits and respite care. Results were not in the expected direction, with significantly more participants in the treatment group being admitted to residential care. The authors offered the explanation that the intervention may have led to situations being identified in which the best option was to admit the person with dementia to residential care. In another study (Jänsson, Almerg, Grafström & Winblad, 1998) caregivers of people with dementia and volunteers were trained together. The volunteers subsequently spent time in the homes of the people with dementia, allowing the caregivers to engage in their own activities. Although formal outcome measures were not used, caregivers stated that they had gained support from meeting others in a similar situation and were very pleased with the care provided by volunteers. The volunteers themselves were very positive about the experience.

In summary, there is some evidence for the efficacy of interventions involving support with caregivers (e.g. Mittelman et al., 1993; Mittelman et al., 1995; Mittelman et al., 1996) although it is limited. Kasl-Godley and Gatz (2000) reviewed interventions for people with dementia and concluded that there have been few systematic studies of approaches such as psychodynamic interventions or support groups. However, there is no real evidence as yet for the efficacy of support groups with people with dementia. Many studies have not used objective measures, but relied on qualitative reports, which are open to bias. Another difficulty has been the lack of control groups.

The wide variability between different support-type interventions makes it hard to compare studies. Finally, support groups tend to be poorly described, making replication difficult. Although support groups were not considered as a possible component in the current intervention due to lack of evidence available for their efficacy, the possible benefits of carrying out group interventions, in terms of the support the participants were reported to have derived from each other, were recognised.

Psychotherapy

Psychotherapeutic approaches have often been poorly described and formal evaluation is limited. Cheston (1998) described psychotherapy for people with dementia as falling into two categories: formal therapy or therapeutic ways of interacting with the person with dementia on a day-to day basis. Formal psychotherapy in this context refers to a range of therapeutic techniques, including

cognitive-behavioural therapy and psychodynamic therapy. In a review of psychotherapeutic approaches, Cheston (1998) highlighted the need for more systematic research and, in a review of psychosocial interventions, Kasl-Godley and Gatz (2000) also pointed out that psychodynamic approaches have not been tested in controlled trials. Some studies, for example Haupt et al. (2000), have used psychotherapy as a component of the intervention. However, in the Haupt et al. (2000) study a range of techniques were used, psychotherapy was not the main focus, and no details about its implementation were described. Consequently, it is not possible to judge what components of the intervention are or are not effective or to replicate the psychotherapeutic component. Cooke, McNally, Mulligan, Harrison and Newman (2001) identified 30 controlled trials in a review of interventions for caregivers and found interventions that had a social aspect or comprised cognitive and social elements were generally most successful.

In view of the fact that few interventions involving psychotherapy have been carried out with people with dementia and those that there are poorly defined and lack any firm evidence, psychotherapy was not considered as a possible component when planning the current intervention.

Counselling

Counselling has primarily been targeted at caregivers for people with dementia. Carers are provided the opportunity to discuss the effect that dementia and resulting problems have had on their lives, and develop problem-solving skills. Zarit et al. (1987) described a study in which caregivers were assigned to an individual and family counselling, support group or control condition. Each treatment condition

consisted of eight sessions, which included information about dementia and coping strategies, with stress management being an important theme. There were no significant differences between the groups. The data were reanalysed by Whitlach, Zarit and Von Eye (1991) using a technique called prediction analysis, which is based on the principle that any substantial changes in some individual scores may still not result in significant findings on standard tests, which look at the mean score. The authors concluded that superior outcomes were demonstrated in the counselling condition using this technique. Finally, a previously described intervention (Mittelman et al., 1993; Mittelman et al., 1995; Mittelman et al., 1996), which consisted of both counselling and support groups, had encouraging findings, but the difficulty lies in accounting for the relative efficacy of each of the types of intervention.

There is a lack of studies that have involved counselling as an intervention, in particular for people with dementia themselves. In addition, there are other factors to take into account such as counselling being just one component of an intervention in some studies that have been described, making it difficult to draw any conclusions about efficacy. Therefore, counselling was not considered as an option in the current study.

Behavioural and cognitive-behavioural interventions

Cognitive behaviour therapy (CBT) refers to a group of therapies that aim to reduce distressing emotions by helping participants to change self-defeating thoughts and behaviours. In CBT the term 'cognitive' refers to the content of people's thoughts as opposed to the cognitive abilities that are assessed during neuropsychological

assessment. Cognitive and behavioural interventions are increasingly being applied to the difficulties people with dementia face, with cognitive approaches generally being reserved for people in the early stage of dementia. CBT interventions have mainly been directed at individuals or couples, but have also taken place on a group basis. They have been used with both people with dementia and their caregivers.

Marriot, Donaldson, Tarrier and Burns (2000) described an intervention aimed at caregivers that consisted of carer education, stress management and coping skills training delivered over 14 sessions. The treatment group was compared with two control groups, one of which received no treatment and the other of which was given a detailed interview to control for therapist attention effects. There was a significant reduction in distress and depression in the intervention group compared to the other two and fewer behavioural difficulties reported for the people with dementia.

A number of interventions have been targeted at the people with dementia themselves. Koder (1998) described two case studies, one of these being an eighty-two year old with vascular dementia who was suffering from anxiety. After seven sessions of CBT, which covered relaxation, cognitive restructuring and distraction techniques, encouraging changes were noted, with the participant going out more frequently and stopping unnecessary visits to her GP. Kipling, Bailey and Charlesworth (1999) described a CBT group that covered a range of techniques including exploration of the link between emotion and memory abilities, identifying unhelpful thoughts and behaviour techniques for anxiety management, such as relaxation. Three men with mild to moderate memory problems took part in the group. Participants were asked to complete self-rating scales to assess change. There were encouraging findings, for example an increase in social activities and the

ability to relax. However, there was less evidence for changes in cognitive abilities. Cooke et al. (2001) identified 30 controlled trials in a review of interventions for caregivers and found interventions that had a social aspect or comprised both social and cognitive elements were generally most successful.

Behavioural approaches have generally been used with people with more advanced dementia. Teri, Logsdon, Upmoto and McCurry (1997) described a study in which caregivers were given training in one of two types of behavioural programme, either looking at how to increase positive events or problem solving. These were compared with a group receiving standard care and a wait list control. Findings showed that depression levels of the people with dementia reduced significantly in both the behavioural intervention groups, although more so for the problem-solving condition. Pusey and Richards (2001) identified forty studies in a review of caregiver interventions and concluded that interventions carried out on an individual basis that made use of problem solving techniques or behavioural strategies were associated with superior outcomes.

In conclusion, cognitive-behavioural and behavioural techniques can be useful approaches for people with dementia but evidence is still limited. Cognitive therapy is usually only appropriate for people with early-stage dementia due to its reliance on verbal abilities and there remain difficulties associated with using thought challenging techniques at times when cognitive functioning is declining, which must be taken into account.

Although there have been fewer CBT studies carried out compared to some other psychosocial interventions, in particular with people with dementia themselves,

findings to date are encouraging.

Summary

As Bourgeois, Schulz and Burzio (1996) pointed out, interventions for caregivers have moved from being descriptive to more empirical, but there are still a number of methodological problems with studies. In a review of caregiver interventions, Pusey and Richards (2001) went as far to say ‘ the lack of current evidence is alarming’. Charlesworth (2001) pointed out that as Pusey and Richards (2001) and Cooke et al. (2001) both reviewed interventions for caregivers, it would be expected that the studies identified would be very similar, which was not the case, although there was some overlap.

Teri (1999) points out that it should be made clear which type of interventions have not worked well, in order that they are not repeated. However, it is also important not to readily dismiss interventions that do not appear to have worked, as they may prove beneficial in different circumstances. Pusey and Richards (2001) state that it is unlikely one type of intervention will be suitable all the time and Charlesworth (2001) pointed out that greater attention should be paid to adapting approaches for different people.

Bourgeois et al. (1996) drew attention to the fact that the content of different types of interventions overlap considerably. This presents issues when trying to determine what the successful components have been in an intervention. Although various theoretical rationales are assumed to underlie each type of intervention, Pusey and

Richards (2001) pointed out that these are not always clear, which presents difficulties when planning future interventions.

A further consideration is the duration of interventions. Thrower (1998) and Glosser and Wexler (1985) found that interventions of a very limited nature were not sufficient to meet the needs of people with dementia or their caregivers respectively. It seems logical that given the complexity of the problems faced by people with dementia and their caregivers, and the fact that new issues will be constantly arising, an intervention should be of a reasonable duration.

However, as Pusey and Richards (2001) pointed out, a longer intervention means it is more likely the control group will seek help elsewhere, especially in view of the fact that dementia is progressive in nature. Furthermore, it is unrealistic to expect any one intervention to meet all the needs of people with dementia and their caregivers. Kitwood (1997) made the point that it is not possible to effectively view a psychosocial intervention in isolation, as is the case for drugs in clinical trials. Instead, the effects of the range of psychological interventions being provided should be considered collectively. However, this does present difficulties in a research context.

Therefore, although psychosocial interventions can clearly have some benefit for both people with dementia and their caregivers, there are important points that need to be considered when reviewing the existing literature. The use of a good research design is essential. This includes objective as well as subjective measures and the use of a control group. Brodaty et al. (2003) found in a meta-analysis of psychosocial interventions for caregivers of people with dementia that interventions

involving both caregivers and people with dementia were generally superior and the authors also pointed out the importance of tailoring interventions to individual needs, which will also be considered.

Rationale for current study

The current study was a group as opposed to individual intervention with the rationale being that participants would derive support from meeting others in similar situations and be able to share ideas and experiences (Yale, 1995). In addition, the aim was that meeting others in a similar situation would decrease sense of isolation in way that individual sessions may not. The fact that participants derive emotional support from each other is supported by past studies (for example, Glosser & Wexler, 1985). Davis (1995) stated that support groups have been invaluable for people with cognitive impairment and reasons for them include providing a therapeutic environment for people who are susceptible to depression and other negative states as a result of a diagnosis of dementia and also that they provide a forum for particular issues for people with dementia to be identified.

The efficacy of group interventions is supported by previous studies in which group interventions have demonstrated significant results in favour of the intervention (Breuil et al., 1994; Magni et al., 1995). In addition, there was the practical consideration that a group intervention meant a service could be offered to a number of people at any one point in time. Criticisms of group interventions were acknowledged, namely that some participants may find interacting in a group as opposed to individual basis more difficult, that some topics may be more effectively

covered on a one-to-one basis and that the support provided by other participants may be confounding in a research context.

Groups were offered to both people with dementia living by themselves and people with dementia and their partners. Providing an intervention to both people with dementia and their partners is associated with superior outcomes, supported by a subsequent meta-analysis by Brodaty et al. (2003). Dröes, Breebart, Meiland, Van-Tilburg and Mellenberg^a (2004) described how integrated family support, involving both the person with dementia and the caregiver, had superior outcomes in terms of feelings of competence of the caregiver and was also associated with delayed nursing home placement of the person with dementia, compared to standard day care for people with dementia. A further study by Dröes, Meiland, Mirjam and Van-Tilberg^b (2004) found significant results for integrated family support for behaviour, depression and self-esteem, compared to standard day care.

The current intervention involved advice on memory strategies and techniques and the aim was that partners could help to implement these at home. This has been done in past studies, for example Quayhagen and Quayhagen (1989). Parallel rather than joint sessions were provided to people with dementia and their partners, as has been the case in past studies (e.g. Aronson et al. 1984), the difference being in the current study that session content was very similar for both. The fact that interventions for caregivers can have an effect on people with dementia is demonstrated by studies such as Haupt et al. (2000) in which there were positive changes in people with dementia following a psychoeducational group for their caregivers. Furthermore, it was felt that there might be issues that partners did not feel comfortable discussing in front of the people with dementia because they might be concerned about upsetting

them and a separate group would provide them with the opportunity to discuss their own feelings and the effect that dementia had had on their own lives. Morris, Morris and Britton (1998) point out that in early stage dementia the responsibility of care usually falls onto the family who at the same time are trying to come to terms with the losses brought about by the diagnosis. In addition, it was recognised that presentation and timing of information within the group would need to be different due to the cognitive deficits of the people with dementia. Finally, as the aim was that the partners would try and help implement memory techniques at home the groups were approached from different angles.

It was decided to implement a multi-component intervention as opposed to one type of intervention in view of the fact that it has been suggested that caregivers are more likely to benefit from this (Brodaty et al., 1997), whilst acknowledging the difficulty of accounting for the efficacy of each of the components of the intervention. Clare (1999) suggested that interventions should target the full range of needs of people with dementia, which lends itself to a multi-component intervention. The intervention consisted of components that have more of an evidence-base and are more applicable to people in the early stages of dementia, namely cognitive-rehabilitation, psychoeducation and cognitive-behavioural therapy. As discussed previously, Clare et al. (2000) showed significant results for five out of six participants following cognitive rehabilitation, Mittleman et al. (1993, 1995, 1996) demonstrated significant results in an intervention that comprised psychoeducation as a core component and Marriot et al. (2000) showed that there was a reduction in distress and depression in caregivers following an intervention comprising cognitive-behaviour therapy techniques. There is also evidence to support the efficacy of these interventions in a group, for example Breuil et al. (1994) found significant

improvements in cognitive test scores following a cognitive stimulation group, Magni et al. (1995) found a reduction in caregiver stress following a psychoeducational group and Kipling et al. (1999) demonstrated encouraging results following a cognitive-behaviour therapy group.

Another reason for including cognitive-behaviour therapy was to explore participant mood, an issue which De Vreese (2001) has pointed out has often not been addressed in cognitive-rehabilitation studies. In addition, as it is widely recognised that dementia can have a negative effect on mood and this in turn can heighten cognitive deficits (Deptula, Singh & Pomara, 1993), it was deemed important to include this as a component of an intervention.

The groups were run for a period of seven weeks. Although the limitations of such a short time period were acknowledged (for example, Glosser & Wexler, 1985) this was due to practical constraints such as low staffing levels. Furthermore, some studies, for example Chiverton and Caine (1989) have shown significant results after a similar period of time. The original aim had been to have a longer intervention (three months) but this was not possible. The plan therefore was that the initial four weeks would focus on cognitive rehabilitation and psychoeducation techniques, the following two cognitive behaviour therapy techniques and the final session would be a summary of what had been covered during previous weeks. This is in line with Thrower's study (1998) during which the initial six sessions covered information about memory and the final two focused on how negative states can affect memory. The format seems logical, in that participants are more likely to feel comfortable discussing emotional issues when they have had chance to become familiar with other group members.

Limitations of past studies, such as lack of objective measures, were taken into account. In the current study formal outcome measures in addition to reports from participants were used. Finally, the fact that it may take time for participants to take new information on board highlights the importance of using follow-up measures and the aim was to incorporate these into the design of the current study.

The primary aim of the intervention was to reduce negative mood states both in people with dementia and their partners. This can heighten cognitive deficits associated with dementia. Objective measures of anxiety, depression, self-esteem and self-efficacy were used to assess this.

For the purposes of the research, stringent inclusion criteria were used when recruiting participants in order to keep the group as homogenous as possible. It was decided that only people with Alzheimer's Disease or Vascular Dementia would be included, in view of the fact that these conditions have reasonably similar profiles which was necessary for the research context and also meant participants would be more likely to share similar experiences. If the outcome of the research was successful, the aim was to offer the intervention to all clients in the service. In view of the reliance on verbal abilities with regards to cognitive behaviour therapy only people in the early stages of dementia could be offered the intervention.

The main aims of the research were twofold. Firstly, the study set out to evaluate the feasibility of the intervention, to determine whether it is acceptable to people with dementia and their families and perceived by them as relevant, and to explore the practicalities associated with its implementation in an everyday clinical setting. Secondly, the study aimed to evaluate the efficacy of

the intervention in terms of observed outcomes for people with dementia and their partners.

The main factor that the intervention was targeting was negative mood states associated with dementia that can lead to excess disability, as cited by Deputula, Singh and Pomara (1993), which again justifies including cognitive-behavioural techniques and also having a group intervention during which feelings and emotions could be shared.

A number of specific hypotheses were tested.

The primary hypothesis was that the intervention would lead to significant improvements in negative mood states associated with dementia for people with dementia.

Secondary hypotheses were as follows:

- a) There will be significant improvements in self-esteem, self-efficacy, family functioning, quality of life, psychiatric symptoms and perceived and actual memory functioning of people with dementia following the intervention.
- b) Partners will report significant improvements in memory problems experienced by the people with dementia following the intervention.

c) Partners will report significant improvements in problematic behaviours displayed by the people with dementia and in their own reaction to them following the intervention.

d) There will be significant improvements in measures of self-esteem, self-efficacy, mood, family functioning and quality of life for partners of people with dementia following the intervention.

e) People with dementia living with partners will show significantly better outcomes from the intervention than people with dementia living by themselves.

g) Any positive effects will be maintained at follow-up.

Chapter 2

Method

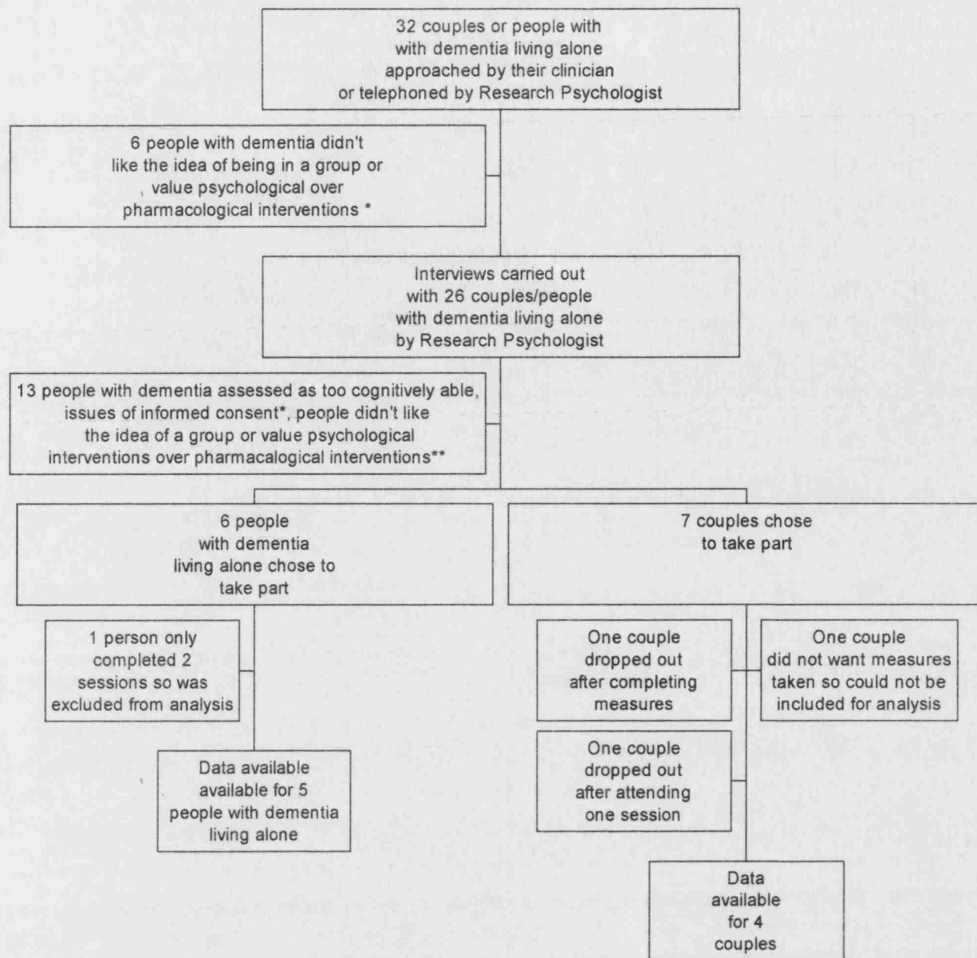
Background to Study Design and Methodology.

The original design is detailed in Appendix 2. Unfortunately, this design, which consisted of a cross-over design using support groups as comparison groups, had to be revised. Some aspects remained as planned (e.g. the measures and the content of the group intervention). However, many of the problems arose from the difficulties associated with carrying out the study in a clinical as opposed to research setting. In addition, there were staff shortages within the Psychology Department for over a year, which resulted in fewer clients being referred to the Psychology Service (although referrals were encouraged from other disciplines, in practice a significant number came from Psychology). Of the potential participants with dementia who were suggested, a number did not meet the inclusion criteria, the primary reason being that they had not received their diagnosis. The lack of potential participants meant that it was not possible to carry out a randomised controlled trial. All people with dementia who were referred and who met the criteria were asked if they would like to participate in the group in order to obtain sufficient numbers. It did not seem realistic to try and carry out either support groups or individual sessions in view of staff shortages. The intervention therefore took place over a 7-week period (as opposed to the 3 month period which had been originally planned). Although the limitations of such a time-limited intervention were recognised, it was felt to be the only viable option in the circumstances. Many examples in the literature are similarly time-limited.

There were a relatively low number of referrals to the groups and a retrospective case-audit was carried out to investigate whether this was a result of there being a small number of people who met the inclusion criteria or whether there were people who met the criteria who were not being referred. Permission for this was obtained from the Trust's Audit Group. Twenty-five sets of notes were accessed, these clients being under the care of one of two psychiatrists, and the audit investigated how many of these clients met the inclusion criteria. The audit was carried out over a period of 3 months. A convenience sample was used of case notes that were available during that time-period.

The following diagram shows the number of people approached and reasons why people did not participate.

Chart showing number of people with dementia and their partners approached



* The Research Psychologist carried out an initial interview and felt that the person with dementia did not understand the concept of the groups being part of a research project. As this person would have been unable to give informed consent he/she had to be excluded from the study.

** where the person with dementia was either judged by the Research Psychologist to not be suitable for the group or decided he/she did not want to participate in the group, and had a partner, the group could not be offered to the partners either. In all cases, it was the person with dementia as opposed to the partner who did not want to participate in the group.

The time period for recruitment was approximately 2 months for Groups A and B and approximately 5 months for Group C. However, a longer length of time (approximately 9 months) was spent trying to recruit participants for a group for people with dementia living on their own and in the end it was not possible to run this due to a lack of participants. Individual sessions for couples were also planned and recruitment took place over 2 to 3 months, although only 2 couples were actually recruited. Reasons for this included the person with dementia being too cognitively able in one case or in other cases the person with dementia either not seeming comfortable with or interested in the course content.

Following each interview with a potential participant, records were made in the client's notes. A research journal was also kept where relevant information regarding the research was recorded, for example qualitative impressions of interviews or peoples' experiences of the groups.

Overview

A seven-session group intervention covering cognitive rehabilitation and cognitive-behaviour therapy techniques, which also had a psychoeducational component, was provided to people with dementia living by themselves and to couples where one person had dementia. Measures were completed by both people with dementia and their partners if applicable at pre-intervention and post-intervention and in some cases at follow-up three months later. Partners of people with dementia were asked to complete measures with respect to themselves and to the people with dementia. Measures were selected which addressed areas it was hypothesised it would be positively affected by the intervention, namely self-esteem, self-efficacy, anxiety,

depression, family relationships, quality of life (for both people with dementia and their partners) and actual and perceived memory functioning and problem behaviours (for people with dementia only).

Participants

The sample consisted of people with dementia living by themselves and couples where one partner had dementia. Participants were recruited from Colchester Memory Clinic and the Older Adults Psychology and Psychiatry Services, Clacton.

The inclusion criteria for the people with dementia were:

1. A probable diagnosis of Alzheimer's Disease or Vascular Dementia and preferably aware of the diagnosis.
2. A score of 18 or above on the Mini Mental State Examination (Standardised)
3. Capable of giving informed consent.
4. Medical condition currently reasonably stable.

Exclusion criteria were as follows:

1. A diagnosis of Frontal Lobe Type Dementia, Parkinson's Disease or other types of dementia.
2. Evidence of long-term psychotic disorder when younger.
3. Evidence of alcohol or illegal drug abuse.
4. Significant hearing or visual problems (which would make it difficult to participate in a group situation).

Thirty-two people with dementia living by themselves or couples where one person had dementia were initially approached about the study, and interviews were carried out with twenty-six of these. Six people with dementia living by themselves and six couples chose to take part, although two couple subsequently changed their minds. A further couple took part in Group B but did not complete the measures as did not want to take part in the research component. From the people who chose to take part, one single person with dementia and two couples did not complete the intervention. Therefore, in total, data were available for nine people with dementia and four partners. The age range of the people with dementia was 70 to 80, with a mean of 76.6 years. Age of partners, which was available in four cases, ranged between 70 and 79, with a mean of 73.5 years.

The main reason for not wishing to participate was not feeling comfortable with the idea of being in a group situation, this being particularly true for the people with dementia. People may have felt that participating in this type of situation would draw their own and others attention to their cognitive deficits. There were a number of cases in which couples were approached and the partner seemed interested in participating but the person with dementia did not wish to, meaning neither could be offered the intervention. Some participants seemed to place much greater confidence in pharmacological interventions for people with dementia and did not appreciate the potential value of combining these with psychosocial interventions. In other cases, it appeared that people with dementia did not meet the inclusion criteria for the study, in particular with regards to capacity to give informed consent. In some instances, even when people with dementia initially seemed to meet the inclusion criteria, it was jointly decided with them that the group would not be appropriate. For example,

in some cases people with dementia were not experiencing difficulties at a level where it was felt the intervention would be useful for them.

Participants were included in the analysis if they completed at least five out of seven sessions. One group (Group A) was run for six people with dementia who were living by themselves. Five participants attended all the sessions, but the other person chose not to continue with the intervention after attending four sessions. Two groups were run for people with dementia and their partners, with sessions for each taking place simultaneously but separately. Three couples initially chose to participate in one of the groups (Group B), although only one couple completed all the sessions. One couple changed their minds about participating and the other attended one session only. A further couple participated in the group but did not wish to complete outcome measures. As no data was collected for this couple they could not be considered in the results. Three couples took part in the other group (Group C). Two of the couples attended all the sessions. One of the people with dementia missed one session due to illness and the same person and her husband were unable to attend another session because they were on holiday. This couple was included in the analysis.

Groups A and B were the first stage of the feasibility study and the procedure and content of the sessions were reviewed for Group C. For the purposes of this discussion the groups will be considered together as in practice differences between them were small.

Design

A pre-test post-test design was used with scores being compared on a range of standardised measures. Following Groups A and B, the procedure, session content and measures were reviewed. Consequently, it was decided to replace a family questionnaire with two self-rating scales for Group C because participants seemed to find the former inappropriate. In addition, Group C participants were asked questions about their goals relating to the group.

Follow-up interviews took place with the majority of participants three months later to assess overall impressions of, and benefits from, the group. Measures were also administered to participants in Group C and the HADS was given to one person with dementia in Group B.

Measures

The following standardised measures were completed at pre-intervention and post-intervention for all participants unless otherwise indicated. They were also administered for Group C at follow-up three months later and one person with dementia from Group B was asked to complete the Hospital Anxiety and Depression Scale at this stage. The measures were administered at participants' homes, this generally taking two sessions with people with dementia and one with their partners.

1. Rosenberg Self-Esteem Scale (RSE; Rosenberg, 1965). Both participants

with dementia and partners completed this with respect to themselves. The RSE consists of ten questions relating to self-esteem, such as whether participants are generally satisfied with themselves, believe they have a number of good qualities and feel they are able to do things as well as most other people. Responses are on a four-point scale with scores between 1 and 4. Lower scores indicate higher self-esteem. Information on the psychometric properties of the scale is limited and norms for older adults do not appear to have been calculated. It is reported that scores for the scale are not normally distributed, with more people obtaining scores indicative of low self-esteem and only 20.1% of adults having the maximum score of 40. Mean scores are cited as being 35.01 for men, 34.52 for women and 34.73 for both.

2. Generalised Self-Efficacy Scale (GSES; Schwarzer & Jerusalem, 1993), completed by both participants with dementia and partners with respect to themselves. The GSES consists of 10 questions that explore perception of coping ability. Responses are on a four-point scale with scores between 1 and 4. Higher scores indicate greater self-efficacy with a maximum score of 40. The mean score obtained from a sample of 1660 participants, who ranged from students to older adults, was 29.28. The scale has been found to have high internal consistency (alphas between 0.82 and 0.93). Retest reliability is cited as being 0.47 for men and 0.63 for women. Correlations with measures of self-esteem, internal control beliefs and optimism range from 0.40 to 0.58. Predictive validity was calculated by comparing self-efficacy with self-esteem and optimism two years later and was found to be 0.40 and 0.56 for women respectively. It was poorer for a sample of men, being 0.20 for self-esteem and 0.34 for optimism.

3. Hospital Anxiety and Depression Scale (HADS; Snaith & Zigmond, 1994),

completed by both participants with dementia and their partners with respect to themselves. The HADS comprises seven questions relating to anxiety and seven relating to depression, with responses being on a scale of 0 to 3. Total scores range between 0 and 21 for each of the sub-scales (anxiety and depression) with Snaith and Zigmond suggesting cut-off scores of 7/8 for possible and 10/11 for probable anxiety or depression.

For anxiety, internal consistency is cited as being 0.80 and the value for depression is 0.81 (Snaith & Zigmond, 1994). Slightly lower figures have been calculated from smaller samples. The correlation for retest reliability has been cited as being more than 0.80 if retesting is carried out within two weeks, although this is lower if more time has elapsed. The mean correlation between anxiety and depression sub-scales has been calculated to be 0.63 in patient groups. Although this reasonably high correlation has led to the question of whether the two sub-scales are independent measures of mood, the explanation put forward is that patients will tend to experience symptoms of both.

A validation study was carried out on the HADS (Snaith & Zigmond, 1994) with 20 participants aged 65 and over who had depression. This showed that the depression sub-scale was valid for this population, although it was not possible to make conclusions about the anxiety sub-scale.

4. The Family APGAR (Smilkstein, Ashworth & Montano, 1982) was completed by both participants with dementia and partners with respect to themselves. This measure was administered to Groups A and B only, being subsequently dropped for Group C who were asked to complete alternative rating scales instead. The Family

APGAR has 5 items relating to perception of family relationships, each of which has three possible responses. Each response is assigned a score of 0, 1 or 2. The total score ranges between 0 and 10, with higher scores indicating greater satisfaction. A version of the Family APGAR is also available in which there are 5 possible responses. The Family APGAR was found to have a correlation of 0.80 with the Pless-Satterwhite Family Index and 0.64 with therapist ratings. There is no data available for older adults or people with dementia, but a study of college students consisting of 291 women and 238 men with an average age of 19.7 years found a median score of 8.1 and a mean score of 7.6. Internal consistency was found to be 0.80. Test-retest reliability was calculated to be 0.83 using a sample of 100 students from the National Taiwan University.

5. Rivermead Behavioural Memory Test (RBMT; Wilson, Cockburn & Baddeley, 1985). This was administered to participants with dementia. The RBMT is designed to measure people's memory in day-to-day activities by a series of tasks, some of which are carried out under immediate and delayed recall conditions. Standardised profile scores are calculated for each task with a score of 2 being considered normal, 1 point borderline and 0 points abnormal. Alternatively, screening scores of 1 or 0 can be calculated for each task. The total sum of standardised profile scores or screening scores can then be obtained. For the standardised profile scores, a total of 22, 23 or 24 is classified as normal, 17 to 21 is indicative of poor memory, 10 to 16 is associated with moderate impairment and 0 to 9 with severe impairment. Age was not found to be associated with performance in a sample of control subjects between 16 and 70, although it is stated that scores are likely to decrease for people over 70. Screening scores were found to be generally lower in a sample of people over 70 compared to younger age groups and scores were also much more variable.

There are four parallel forms of the RBMT (A, B, C and D). A different version should be used each time testing is carried out with the same individual. The reliability of the parallel forms has been calculated by comparing both the standardised profile scores and screening scores of version A with versions B, C and D. Values for standardised profile scores were calculated as 0.86, 0.83 and 0.88 and those for screening scores are 0.84, 0.80 and 0.67 respectively.

A value of 100 percent was found for inter-rater reliability using a sample of 10 raters. Test-retest reliability was calculated using a sample of 118 patients, and found to be 0.85 for standardised profile scores and 0.78 for screening scores. The mean level of performance of participants in the two testing sessions was also calculated. For standardised profile scores, the mean was 15.29 in the initial testing session and 16.05 on the second. There was a significant difference between performance on one item, remembering a belonging, in the two testing sessions.

The variability was also calculated by comparing the RBMT with other memory tests: the Warrington (1984) Recognition Test for words and for faces, digit span, spatial span using the Corsi block technique, the paired associate test (Randt, Browne & Osborne, 1982) and a sentence verification task (Baddeley, 1981). With regards to the standardised profile score, correlation values of between 0.20 and 0.63 were obtained. There is also evidence that the RBMT is a good task of everyday memory.

Norms for older adults were investigated by testing a sample of 119 participants between the ages of 70 and 94 years old. There were 44 men and 75 women in the sample and the mean age was 80.49 years old. Not all participants were able to

complete all the tests for various reasons, including visual deficits. Results showed that age did have a clear effect on scores obtained, which were lower than for younger participants.

5. Memory Awareness Rating Scale (MARS), Clare, Wilson, Carter, Roth & Hodges. (2002).

There are three parts of the MARS. The participants with dementia completed two parts of the MARS with respect to themselves. Partners completed the other part of the MARS with respect to the people with dementia.

i) Participants with dementia were initially asked to complete the self-report version of the MARS (MARS-MFS-S, Clare et al., 2002). The MARS-MFS-S consists of thirteen questions that ask how respondents feel they would manage in everyday situations such as remembering someone's name, an appointment or a route around a building. Responses are given on a five-point scale with a score between 0 to 4 assigned to each of these. The total score ranges between 0 and 52, with higher scores indicating perceived better memory functioning. Psychometric properties have been calculated with people with early-stage Alzheimer's Disease. Internal consistency has been calculated as 0.94, retest reliability as 0.91 and criterion validity, using comparisons with the Memory Insight Questionnaire and Memory Symptoms Questionnaire, as 0.71 and 0.74 respectively.

ii) Partners were asked to complete the informant version of the MARS (MARS-MFS-I, Clare et al., 2002). The MARS-MFS-I consists of thirteen questions that cover identical situations to those in the MARS-MFS-S. Respondents are asked to

rate on a five-point scale how they believe their partner would be able to cope in the situations, with scores for each response ranging from 0 to 5. The total score ranges between 0 and 52. Psychometric properties of the scale have been calculated using a sample of partners of people with early-stage Alzheimer's Disease. Internal consistency has been calculated as 0.94 and retest reliability as 0.9.

The discrepancy of ratings between the person with dementia and the informant (in this case, partner) can then be considered.

iii) The people with dementia were also asked to complete the performance scale of the MARS (MARS-MPS; Clare et al., 2002), for use in conjunction with the RBMT. The MARS-MPS consists of thirteen questions relating to each section of the RBMT, asking respondents to rate how they believe they performed in each sub-test after it has been completed. Answers are given on a five-point scale, with scores on each ranging from 0 to 4. These scores are adjusted for purposes of analysis. The total score ranges between 0 and 52, with the higher the score the better the participant's rating of their performance. Psychometric properties have been calculated from a sample of people with early-stage Alzheimer's Disease and their partners. The alpha for internal consistency has been calculated as 0.93 and retest reliability as 0.97 for people with dementia and 0.97 for partners. Participants were asked to complete three sections of the Memory Awareness Rating Scale (MARS). The MPS can be used to look at the difference between how people with dementia rate their memory ability and their actual test scores gained on the RBMT. In addition, the tasks in the MPS are analogues of the situations in the MFS, thus allowing a comparison of responses between the two scales. If there are differences between these two it

suggests either a lack of awareness or insight into memory problems or denial of memory difficulties.

7. A clinician rating scale, the BEHAVE-AD (Reisberg et al., 1986) was completed for participants with dementia for Groups A and B only. The BEHAVE-AD addresses behaviour that may be exhibited by people with Alzheimer's Disease. Part 1 consists of 25 questions that fall under the following 7 categories: paranoid and delusional ideation, hallucinations, activity disturbances, aggressiveness, diurnal rhythm disturbance, affective disturbance and anxieties and phobias. Part 2 comprises a global rating question that addresses the extent to which the caregiver is adversely affected by any behaviours. There are 4 possible responses to each question, with a score between 0 and 3 being associated with each. The range of scores on Parts 1 and 2 are 0 to 75 and 0 to 3 respectively.

The BEHAVE-AD has been evaluated using both US and French-speaking populations (the latter with the French version of the measure) and mean scores were calculated in another sample of 140 people with a diagnosis of probable AD. It was found that problematic behaviours are more likely to occur in the middle to late stages of dementia.

8. Scores on the Standardised Mini Mental State Examination (SMMSE, Molloy & Standish, 1997) given at the time points that best approximated to pre-intervention, post-intervention and follow-up were taken from the casenotes of participants with dementia in Group C only as part of the revised protocol. The SMMSE covers a range of aspects of cognitive functioning including orientation to time and place, short and long term memory and registration and recall with a maximum possible

score of 30. Lower scores indicate greater impairment. The SMMSE was introduced as a result of the wide variations in method of administration of the MMSE. The reliability of the MMSE and SSMSE were compared in a sample of 48 older adults (Molloy & Standish, 1997) with the tests being carried out three times. As anticipated, the inter-rater and intra-rater reliability were greater for the SMMSE than the MMSE and this difference was significant. For the SMMSE, the inter-rater and intra-rater variance was reduced by 76% and 86% respectively.

9. Revised Memory and Behaviour Problem Checklist (RMBPC, Teri et al., 1992), which was completed by partners with respect to the participants with dementia. The RMBPC consists of twenty-four items for which respondents are asked to rate both the frequency of behaviours observed in the person with dementia and their reactions to these. Answers are given on a five point scale, with scores ranging between 0 and 4 and there is further category for 'don't know/not applicable' responses. The total score for both frequency and reaction ratings is between 0 and 96. Alpha ratings for internal consistency were calculated using a sample of older adults and found to be 0.75 for frequency and 0.87 for reaction. The questions can also be divided into three sections which are: memory related, depressive and disruptive behaviours.

10. Family functioning and life satisfaction rating scales. People with dementia and their partners in Group C only were asked to complete two questions with respect to themselves, which were as follows:

1. Do you feel able to talk to your family about your/your partner's memory problems?

2. How happy are you with your life as it is now?

Each scale has five possible responses ('always, often, sometimes, rarely, never' for the first question and 'very unhappy, quite unhappy, neither happy or unhappy, quite happy and very happy' for the second) with scores ranging between 1 and 5 assigned to each. Higher scores indicate perceived greater potential for communication with family and a higher degree of life satisfaction. These were developed for the present study.

Qualitative measures

For Group C, people with dementia and their partners were asked whether they had any goals they hoped would be met by the course prior to its commencement. At post-intervention, a series of four questions were asked which were as follows:

1. whether any previously stated goals had been met
2. whether participants remembered any memory strategies or techniques from the course
3. whether these were being used prior to the course
4. whether any memory techniques were being implemented as a result of the course.

At follow-up, if it had previously been stated that goals had been met by the course it was asked whether this was still the case. If participants had stated that memory aids

were being used subsequent to the course, questions 2 and 4 above were asked again to ascertain whether these were still in place.

Other measures

If participants had been prescribed an acetylcholinesterase inhibitor this was recorded. For Group C any health services, social services or voluntary organisations the people with dementia were involved with were recorded.

Administration of measures

The administration of measures took place at participants' homes. This generally took place over two sessions for people with dementia and one session for partners. In Session 1 for people with dementia, the RSE, GSES, HADS and MARS –MFS-S were usually administered and participants in Group C were also asked about their goals relating to the Memory Group. The other measures (RBMT, MARS-MPS and Family APGAR or Family Functioning/Life Satisfaction rating scales) were administered in Session 2. Each session was approximately an hour in duration. The fact that testing for people with dementia took longer was a result of their comparatively lower cognitive abilities and the fact that more measures were administered. Where possible, measures were administered within two weeks of the beginning and end of the group in order that any changes could be more confidently attributed to the intervention.

In cases where the person with dementia and their partner were both being tested, it was felt that participants would probably prefer to complete this stage as quickly as

possible. Therefore, two people visited initially, one to carry out measures with the person with dementia and the other with the partner. It was also felt that if the same person had administered measures to the person with dementia and the partner, this may have made it harder to establish rapport. Measures were administered by Clinical Psychologists, Assistant Psychologists and a Research Psychologist (myself). In many cases, the people who administered the measures were also the group facilitators. While this was recognised as not being ideal it was the only viable option with the staff numbers available.

Procedure

Applications were made prior to the study to the local Ethics Committee and the Trust's Research and Development Group and permission to proceed was granted (see Appendix 3). Prior to the groups, a training day took place on key areas from cognitive-rehabilitation and cognitive-behaviour therapy. All professionals who would be facilitating the groups participated. When sessions were subsequently devised by the Research Psychologist (myself) account was taken of feedback received on the training day. Following Groups A and B, the procedure, selection of measures and intervention were revised for Group C. A manual was compiled by the Research Psychologist for use by professionals who would be involved in the research in the future. The manual included the following: background information relating to the research, an overview of psychosocial interventions in the Trust, the research protocol, with two versions - 'Patient only' (for people living by themselves) and 'Patient and Partner' (for couples) - information sheets, a copy of the measures, session content and key references. In addition, the decision was made to refer to the intervention as a 'Memory Course' as opposed to 'Memory Group'

following the first two groups as it was felt the latter term may be more likely to invoke apprehension.

For Groups A and B, referrals came from the Psychology Department only, although referrals from other professionals in the Trust were encouraged. The nature of the group was explained to potential participants by a clinician already working with the person with dementia. If they (and their partners if applicable) were interested, this was taken forward. In the case of people living by themselves, permission was sought to contact one of their relatives to explain the study to him or her.

Due to unexpected circumstances there were staff shortages within the Psychology Department that resulted in fewer clients passing through the service and subsequently less opportunity for the identification of potential participants. It was therefore decided that other professionals working in the service should be more formally approached to recruit participants for Group C. Referral forms and information about the study were sent out to consultant psychiatrists and community psychiatric nurses in the Trust by the Research Psychologist and it was asked that any clients who met the criteria either at that point in time or in the future could be identified. In practice, it was the Research Psychologist (myself) who checked through case-notes to determine whether inclusion criteria were met once names of people with dementia and/or their partners were put forward. Permission from the appropriate psychiatrist was sought before accessing case-notes. The names of a number of potential participants who did not meet the inclusion criteria were put forward and these people could not be included in the study. Health professionals were asked not to mention the study to clients of the service and their partners until the Research Psychologist had confirmed that the inclusion criteria were met. This

was to ensure people were not offered an intervention it was subsequently not possible to provide. One psychiatrist did mention the study prior to the Research Psychologist confirming inclusion criteria were met in order to gauge degree of interest, but this person checked the inclusion and exclusion criteria himself and made it clear to clients and partners that the opportunity to participate in the study was only a possibility. In cases in which referrals were made from a health professional other than the psychiatrist, the Research Psychologist checked that the named psychiatrist for the person was happy for him or her be contacted before proceeding.

Once the Research Psychologist had confirmed that inclusion criteria were met, potential participants were ideally approached by a clinician involved in their care to determine whether or not they would be interested in participating in a Memory Course (this has since become a procedure that the local Ethics Committee stipulate needs to be followed). If the response was affirmative, people were subsequently contacted by the researcher. In other cases, potential participants were contacted directly by the researcher by telephone after their names had been put forward by a clinician.

If people stated they were interested in participating, they were either seen in the clinic after an appointment with their Consultant Psychiatrist or Psychologist or a visit was arranged to their homes to discuss the study in more detail. It was made clear that people's decision had no effect on the other services received from the Trust. In addition, it was pointed out that if people did decide to take part transport could be provided by the Trust if necessary. People interested in participating were provided with an Information Sheet and asked to sign consent forms either on this

occasion or on a second visit. This was decided on the basis of whether it was felt it would be easier for the people with dementia to break down the provision of information into two sessions. In some cases, after being provided with the key information people seemed undecided and they were left to make the decision in their own time. If people did subsequently decide they would like to participate, further visits were arranged.

At the beginning of the initial session for Groups A and B participants were asked to discuss what group rules they would like in place. Group C were sent a list of group rules prior to the initial session, which were as follows: all participants should be given the opportunity to speak but it was also fine if people chose not to, confidentiality relating to other participants should be maintained, and all sessions should begin on time. These rules were discussed at the initial session of Group C, to confirm that participants understood and agreed with them and in order that any further rules participants would like could be added.

As stated, Group A was for people with dementia living on their own. In the case of Groups B and C, sessions for people with dementia and their partners took place separately but simultaneously. Three people facilitated Group A, these being a Clinical Psychologist, Trainee Clinical Psychologist and Assistant Psychologist. For Groups B and C, two facilitators led the session for people with dementia and two other facilitators the partners' session. For Group B, an Assistant Psychologist and Trainee Clinical Psychologist ran the group for people with dementia and an Occupational Therapist and Research Psychologist (myself) facilitated the sessions for partners. With respect to Group C, the group for people with dementia was led by an Assistant Psychologist and Research Psychologist (myself) and the partners'

group was facilitated by an Occupational Therapist and Assistant Psychologist. The main benefit of having professionals from both Psychology and Occupational Therapy involved was the range of skills that were brought to the intervention. Having more than one facilitator meant sessions could still take place if a member of staff was on holiday or sick-leave, which were events that occurred on a number of occasions. It also meant that one person could lead the group while the other provided individual support and encouragement to participants. Ideally, the same two facilitators ran each session. However, the groups for partners tended to be easier to facilitate as participants were generally more talkative and generated their own discussion topics to a greater extent than people with dementia. Therefore, on one occasion when there was only one facilitator available for Group C's session for people with dementia, a facilitator from the partner's session joined the group for that week. In the final week of Group C, a Clinical Psychologist was asked to join the session for the people with dementia as it was felt he might be able to offer a valuable insight into group dynamics. Participants were asked beforehand if they felt comfortable with the idea of a different person being present.

The intervention is discussed in detail below. For all the groups, entries were made in the case-notes of the people with dementia following each session. For Group C, standard recording sheets were also completed after each session. The purpose of doing this was to monitor that the protocol was being adhered to and record any topics generated by participants, with those covered in the most and least detail noted and a general summary of the session provided. Prior to the study, it was made clear to all participants that it was fine for them to withdraw at any time. However, it was noted that the people with dementia in Group C seemed less keen to attend than their partners. It was felt that the people with dementia might have been persuaded to

attend by their partners who wished to come to the group themselves. Therefore, it was made clear to all the participants that it was fine for partners to attend even if the people with dementia did not wish to, providing the latter were comfortable with this idea because of the fact that issues relating to them would be discussed.

Participants were encouraged to discuss their impressions of the group and whether it was meeting their expectations throughout the sessions. In the final session, participants were asked to give their overall opinion of the group. Evaluation forms were also subsequently sent out which asked participants which topics they had found most and less useful, any suggestions for how future groups could be improved and any general comments. Letters were sent to the GPs of the people with dementia and relevant health professionals, providing a brief summary of each participant's involvement. Measures were completed again after the group and interviews took place with the majority of participants at follow-up three months later, with measures being administered in some cases.

Another group for people with dementia living on their own had also been planned, but unfortunately few people were referred and from these an insufficient number of people expressed an interest in participating for it to take place. In addition, it was planned to offer sessions to people with dementia and their partners on an individual as opposed to group basis. However, only two couples were identified where the person with dementia met the criteria for the intervention and neither of these completed the sessions. One couple completed only three sessions and the other five.

Intervention

Tables 1 and 2 show the number of participants and facilitators in each group.

Groups B and C for people with dementia and their partners were split into sub-groups during the session as shown in Table 2.

Table 1. Participants in Group A

Group A (people with dementia living by their self)	No. of participants completing 5 or more sessions	No. of facilitators
	5 (one person dropped out)	3

Table 2. Participants in Groups B and C

Groups for couples	No. of people with dementia completing 5 or more sessions	No of facilitators	No. of partners completing 5 or more sessions	No of facilitators
B	2 (measures only taken for one)	2	2 (measures only taken for one)	2
C	3	2	3	2

All groups lasted for seven weeks and drew on techniques from cognitive rehabilitation and cognitive-behaviour therapy. They also had a psychoeducational component. Session content was similar for all groups but, as previously stated, was revised slightly for Group C. Groups for people with dementia and partners followed similar protocols, but the latter focused on ways they could help introduce memory aids and strategies. Session content for the groups was as follows:

Stage 1 of Feasibility Study (Group A for people with dementia living by themselves and Group B for people with dementia and their partners).

Week 1: Introduction to dealing with memory problems. The session started with a discussion of the group rules that participants would like in place. During this session the following were discussed; models of different types of memory (e.g. long and short-term), types of information that need to be remembered, (e.g. personal information, skills, verbal and visual information) and the stages of the memory process, encoding, storage and retrieval.

Week 2: Memory aids. This session looked at the memory aids that people were currently using and went on to consider other types of memory aids that might be helpful. The types of memory aids that were discussed were; diary, filo-fax, wipe clean memo board, notepad by the telephone to write down messages, writing a 'to do' list, day by day calendar, pill reminder box and alarm clock or timer. It was discussed how participants with dementia might find it difficult to use new memory aids at first and that reminders are likely to be required from family or friends, but after a while it should become easier and more automatic to use the memory aid. Another point that was covered was that people tend to find that some memory aids suit them whilst others do not, so therefore it is important for the individual to find a memory aid that is suitable for him or her.

Week 3: Taking in information – visual and verbal strategies. The ways participants found they could take in information more effectively were looked at and whether verbal or visual techniques or a combination of both worked best. These were considered under the three stages of memory, encoding, storage and retrieval. Techniques covered included with regards to encoding were reducing the amount of information that needs to be remembered, dividing information into small chunks,

taking time to remember and paying attention, repeating the information to be remembered, organising information that need to be remembered under categories, using two or three different methods to remember a piece of information, mnemonics and errorless learning. With regards to storage it was discussed how new information can be forgotten very quickly and one way to prevent this is rehearsal and the concept of expanding rehearsal was introduced. Finally, retrieval was considered and how remembering is easier if surroundings and mood are the same as at encoding.

Week 4: Maintaining a helpful environment. This session looked at how the environment could be used to help with memory by cues and reminders being used in the home. It went on to explore how other people, for example members of the family, could help. Techniques covered included having a set place for items in the home, having items used most frequently in an accessible place, having a newspaper delivered daily to act as a prompt for date and the day of the week, having photographs of family and significant others around the house, keeping a memory book and putting labels on drawers.

Week 5: Taking in information – how feelings affect memory. The fact that thoughts and emotions can affect memory was discussed. The session went on to look at techniques participants could use to identify when feelings and emotions were making remembering more difficult. It was considered how memory works more effectively when the person is focused on the topic, can hear and see the information adequately and feels relaxed. Situations that can cause memory to work less well were also looked at, including feeling worried, anxious or depressed or being preoccupied. It was also discussed how everybody forgets but that the person with

dementia is more likely than others to focus on these incidences. Ways of helping negative mood states were also looked at, namely distraction techniques, breathing exercises and relaxation techniques.

Week 6: Forgetting gracefully – coping in social situations. Techniques that participants could use to cope with situations in which they forgot information were explored and ways in which friends and partners could help were looked at. The session went on to discuss how participants should reduce unhelpful expectations or standards they had regarding themselves.

Week 7: Open session and review. This session was left open to cover any issues arising and to review the work that had been covered.

Stage 2 of Feasibility Study (Group C; People with dementia and their partners).

Week 1: Introduction to dealing with memory problems. This session started with discussion regarding which types of information needed to be remembered, for example facts and personal experiences and different types of memory (episodic and semantic, short and long term). The three stages of memory, encoding, storage and retrieval were then looked at and it was discussed how failure at any one of these stages would lead to information being forgotten. A group exercise was then carried out during which participants were asked to recall items from a list (items to be taken away on holiday). This was then used as a discussion point to demonstrate that most people would not be able to remember all the items on the list, the fact that participants with dementia were able to remember some items demonstrated that

memory was working to an extent (this point was raised specifically in the group for the people with dementia as opposed to the group for partners), how long-term memory may have helped some participants recall some of the items (knowledge of what someone would usually take away on holiday) and whether participants had used any techniques to help them remember the items.

Week 2: Memory aids. Participants were asked whether they or their partners were currently using memory aids and it was discussed how helpful these were. The distinction between internal and external memory aids was made and it was discussed how the latter are generally more useful for people who have memory problems, but that these still rely on the use of internal strategies. For example, a calendar is an external memory aid but people still need to remember to look at it. Examples of memory aids were generated including calendars, diaries, note-pads, pill reminder boxes, newspaper, lists, memo boards, photo albums and memory books. Further discussion points were that people sometimes feel that using memory aids will prevent their memory from improving but there is no evidence to support this, that people usually need to try a range of memory aids before they find what works best for them, how it can help if family or friends can remind the person with dementia to use the memory aids when they are starting to use them, how having a tidy environment is beneficial because items are less likely to be mislaid and how a regular routine can also help. Finally, participants were encouraged to generate examples of any areas they/their partners were experiencing particular difficulties with and possible memory aids it might be useful to try in those situations were discussed. Participants were encouraged to try any new memory aids at home prior to the next session.

Week 3: Taking in information - visual and verbal strategies. The session began with asking participants if any new memory aids had been implemented at home following the last session. Visual and verbal techniques to remember information were then explored. The point was made that when people have difficulties with their memory they will require extra support at encoding and retrieval. Practical ways to do this were then covered. Techniques with regards to encoding included ensuring the information can be seen and heard adequately, feeling alert and spending time trying to remember information, trying to remember one piece of information at a time, using several senses at any one time, errorless learning and mnemonics. With regards to retrieval, methods covered were going through the alphabet to try and recall the first letter (and subsequently the whole name) of an item and doing a task with someone else initially.

Week 4: Maintaining a helpful environment. This session focused on ways of adapting the environment to facilitate memory. As in previous sessions, participants were encouraged to generate their own examples of strategies they/their partners used. Techniques such as keeping important items in a certain place, putting items used most frequently in an accessible place, leaving items that need to be taken out by the door, labelling containers, arranging clothes in order in the drawers and having a set routine were discussed. It was discussed how family and friends can help the person with dementia by facilitating the use of some of these techniques.

Week 5: How we feel affects our memory. This explored how negative emotions such as anxiety, depression, being preoccupied, thinking about the past and future as opposed to the present and fearing that the worst will happen can make memory problems worse. The point was made that people with dementia are more likely than

other people to focus on the times that they forget information. Ways of improving these negative states such as positive thinking and relaxation were explored.

Participants were asked to generate any examples of strategies that they found helpful and the following techniques were looked at; talking about feelings, distraction, not thinking in all or nothing terms and trying to think of positive events that had happened recently.

Week 6: Coping in social situations. One problem the people with dementia seemed to find particularly difficult was forgetting people's names. Techniques to help with this were discussed, such as picking up cues from the situation, going through the alphabet to try and remember the first letter of the name making subsequent recall of the name more likely or simply asking the person. Partners were provided with suggestions as to how they could help when with the people with dementia, such as using the person's name in the conversation.

Week 7: Overview. An overview of topics covered in all the sessions was provided and participants were provided with the opportunity to revisit any areas in more depth. The key points were revisited; memory aids, taking in information, adapting the environment and how feelings affect memory. Participants were encouraged to discuss how they had found the course and what had been most and less helpful.

In each case, Session 1 began with an overview of what was to be covered in future sessions. Each subsequent session began with a summary of what had been covered the previous week and a discussion as to whether participants had tried any techniques at home, before proceeding with the topic for that week. A flip-chart was used to record the main comments from participants as this was felt to be a useful

way to remind both participants and facilitators of what had been discussed.

Exercises were included in some of the sessions in order to maintain interest and demonstrate any relevant concepts. Each session for Group A took approximately an hour and a half, with tea and coffee being provided. The groups for couples followed a slightly different format. Each session begun with a social meeting lasting between 20 minutes and half-an-hour for both people with dementia and their partners, during which time refreshments were provided. The idea behind this was that it gave all participants the opportunity to get to know each other, which was particularly important in view of the fact that people with dementia and their partners would be in different groups. It also meant that people did not have to feel concerned if they were slightly late (particularly if relying on public transport) and sessions could still begin on time. The people with dementia remained in the original room while their partners were then asked to go to a different room. It was felt that the people with dementia might find it easier if they remained in the same room throughout.

Each group session lasted approximately one hour. Session content was similar for both people with dementia and their partners, but the latter focused on ways they could help to implement memory aids at home and it also provided a forum for them to discuss their own experiences. Participants were encouraged as far as possible to generate their own examples relating to their own or their partner's memory difficulties, and techniques that could be used in each situation were discussed. If participants chose to discuss related issues that were not in the protocol, this was encouraged, as the purpose of the group was also to provide a supportive function. At the end of the session, partners rejoined the people with dementia. In Group C, participants always chose to spend some time talking after the session had closed before leaving. Handouts detailing topics covered were compiled following each

session of Group A and B and subsequently sent to participants. Group C were given standard handouts at the end of each session, some of which varied slightly for people with dementia and their partners. Two social meetings for Group C have since taken place at the clinic at the request of participants.

Overview of data analysis

Descriptive analysis was carried out for all the measures with means, modes, ranges and standard deviations being calculated. It was only possible to carry out statistical analysis on the measures that a sufficient number of participants had completed at both pre-intervention and post-intervention. This meant that it was not possible to test all the hypotheses stated in Chapter One. The majority of participants had not completed follow-up measures and therefore it was not possible to carry out statistical analysis on this data.

A Wilcoxon Signed Ranks test was used because the study used a repeated measures design. Groups A, B and C were combined for the purposes of analysing the results.

Group A was for people with dementia and their partners, Group B was for people with dementia living by themselves and Group C was the revised group for people with dementia and their partners. Participants with dementia and four partners completed measures at pre-intervention and post-intervention. From these, three people with dementia and three partners completed measures at follow-up three months later and one person with dementia completed the Hospital Anxiety and Depression Scale but no other measures at this point in time. Sets of measures were incomplete for some of the participants. This was usually due to participants not

feeling measures or particular items on them were applicable to them. As previously stated, there were some differences in the measures completed for Groups A and B compared to Group C. Groups A and B completed the Family APGAR, and the BEHAVE-AD was completed on the behalf of the people with dementia. Group C completed the Family Relations and Quality of Life questions, and Mini Mental State Examination (Standardised) scores were taken from their notes. Due to the fairly small number of participants identified for the groups, it was decided it would be useful to look at how many clients in the service would have met the inclusion criteria. A case-note audit was carried out during which this question was addressed. A submission was made to the Trust's Audit Group for permission to do this and the results are presented in Chapter 3.

Since measures were incomplete in some cases, there were insufficient numbers to carry out statistical analysis on some of the measures completed by participants with dementia. A Wilcoxon Signed Ranks Test was used to determine whether there were any statistical differences on scores obtained at pre-intervention and post-intervention on the measures displayed in Table 1. The data did not meet the criteria for a parametric test. There were only four partners in total in the study, which was not a sufficient number to carry out statistical analysis on the partners' data.

Chapter 3

Results

Overview

In this chapter, quantitative findings are considered with respect to the primary and secondary hypotheses and qualitative findings are discussed. Results are considered on a group and individual basis, moving onto the results from the case-note audit that looked at how many people with dementia being seen by the service would have met the inclusion criteria and finally looking at qualitative findings. The findings are then considered with regards to the overall research question, which was to evaluate the feasibility and efficacy of the intervention. As stated in Chapter 2, stages 1 and 2 of the feasibility study were combined for the purposes of analysis. Nine people with dementia and four partners completed the measures at pre-intervention and post-intervention. From these, three people with dementia and three partners completed measures at follow-up three months later and one person with dementia from one of the couples completed the Hospital Anxiety and Depression Scale but no other measures at this point in time. Sets of measures were incomplete for some of the participants. This was usually due to participants not feeling particular measures or items were applicable to them.

The sections are as follows:

- 1. Group results evaluated against the hypotheses, comparing pre-intervention, and post-intervention and follow-up where applicable.**

2. Individual results.

3. Results of case-audit.

4. Qualitative information.

1. Group results

a) People with dementia

Mean scores, standard deviations and ranges were calculated for measures at pre-intervention, post-intervention and follow-up (see Table 1). A Wilcoxon Signed Ranks Test was used to determine whether there were any significant changes from pre-intervention to post-intervention on those measures for which there was sufficient data.

Table 1. Means, standard deviations, range, number of participants with dementia completing each measure (n), p-values and significance (S= significant and NS = non-significant) for all participants with dementia

NC =not completed

Measure (and range of scores possible to obtain)	Pre intervention Mean SD Range Participants	Post Intervention Mean SD Range Participants	Follow-up Mean SD Range Participants	P-value	Level of significance (at.0.5 level)
HADS Anxiety Scale (0-21) (Lower scores = lower anxiety)	6.29 3.251 3-11 n = 7	8.14 3.546 4-12 n = 7	NC	0.066	NS
HADS Depression Scale (0-21) (Lower scores = lower depression)	3.14 3.185 0-8 n = 7	3.43 3.155 0-9 n = 7	NC	0.317	NS
RSE (10-40) (Lower scores = higher self – esteem)	21.6 2.217 19-24 n = 5	21.6 0.577 21-22 n = 5	NC	1.000	NS
GSES (10-40) (Higher scores = higher self-efficacy)	31.33 4.082 28-37 n = 6	30.33 3.077 27-35 n = 6	NC	0.416	NS
Memory Functioning Scale, Self Report Version (0-52) (Higher scores = greater reported memory ability)	42 3.63 37 –46 n = 6	38 1.79 35- 40 n = 6	NC	NC	NC

Measure (and range of scores possible to obtain)	Pre intervention Mean SD Range Participants	Post Intervention Mean SD Range Participants	Follow-up Mean SD Range Participants	P-value	Level of significance (at 0.5 level)
RBMT – Standardised Profile Score (0-24) (Higher scores = greater cognitive ability)	8 6.75 2-8 n = 5	2.5 7.31 2-3 n = 5	NC	NC	NC
MARS – Performance Scale (part of) (0-52) (Higher scores = higher performance)	29.6 9.81 17-41 n = 5	27.8 11.90 9-37 n = 5	NC	NC	NC
Family APGAR (0-10) (Higher scores = higher reported family networks)	10 0 10 n = 2	9.5 0.71 9-10 n = 2	NC	NC	NC
BEHAVE-AD Part 1 (0-75) (Lower scores = fewer behavioural difficulties)	1.33 2.31 0-4 n = 2	0.33 0.58 0-1 n = 2	NC	NC	NC
BEHAVE-AD Part 2 (0-3) (Lower scores = fewer behavioural difficulties)	0 0 0 n = 2	0 0 0 n = 2	NC	NC	NC
Family Relations Question (1-5) (Higher scores = higher reported family functioning)	3.67 1.56 3-5 n = 3	4.33 0.58 4-5 n = 3	4.33 1.16 3-5 n = 3	NC	NC

Measure (and range of scores possible to obtain)	Pre intervention Mean SD Range Participants	Post Intervention Mean SD Range Participants	Follow-up Mean SD Range Participants	P-value	Level of significance (at 0.05 level)
Quality of Life Question (1-5) (Higher scores = higher reported quality of life)	4.5 0.71 4-5 n = 2	4.5 1.41 2-4 n = 2	4 0 4 n = 2	NC	NC

As can be seen from Table 1, there are no notable differences between mean scores obtained by people with dementia at pre-intervention and post-intervention on any of the measures apart from the anxiety scale of the Hospital Anxiety and Depression Scale, which showed an increase of anxiety ratings although this was not significant and the Rivermead Behavioural Memory Test where scores dropped substantially from pre-intervention to post-intervention.

Each of the measures is considered below in turn.

1. Hospital Anxiety and Depression Scale (HADS), Anxiety Scale. Lower scores mean there are fewer symptoms of anxiety. There was a negative trend for anxiety, with the mean score shifting from within the normal range to the range that indicates the presence of possible anxiety. However, the actual change in points on the scale was small and the ranges were similar at pre-intervention and post-intervention. The standard deviation was similar at pre-intervention and post-intervention.

2. Hospital Anxiety and Depression Scale (HADS), Depression Scale. Lower scores indicate less depressive symptomatology. The mean score obtained at pre-intervention was within the normal range, meaning there was little scope for depressive symptomatology to decrease. Although the mean score for depression had not significantly reduced at post-intervention, neither did it increase. The standard deviations were similar at pre-intervention and post-intervention.

3. Rosenberg Self-Esteem Scale (RSE). Lower scores indicate higher self-esteem. The mean scores were identical at pre and post-intervention. The standard deviation was greater at pre-intervention than post-intervention, but taking these figures into account, the mean scores were all substantially lower (indicating higher levels of self-esteem) than the score calculated for the general population (35.01) meaning there was little scope for improvement. The range of scores was slightly greater at pre-intervention.

4. Generalised Self-Efficacy Scale (GSES). Higher scores indicate greater self efficacy. Mean scores were similar at pre-intervention and post-intervention. The fact that the mean score was high initially means there was little opportunity for improvement on this measure. The standard deviation was slightly greater at pre-intervention. Taking the standard deviation scores into account, some of the mean scores fell in the range of the mean calculated for the general population (29.28), but some were notably higher than this figure.

5. MARS (Memory Functioning Scale)- Self Report Version. Higher scores indicate that participants rate their memory abilities more highly. There was only a slight fall in the mean score from pre-intervention to post-intervention, indicating there were no

notable changes in the way participants rated their memory performance. The standard deviation and range was slightly greater at pre-intervention.

6. Rivermead Behavioural Memory Test (RBMT). The mean standardised profile score fell from pre-intervention to post-intervention, indicating poorer performance at post-intervention. The standard deviation was greater at post-intervention for both sets of scores.

7. MARS (Memory Performance Scale). This measure looks at how participants rate their performance on the RBMT. Mean scores on the MPS were similar at pre-intervention and post-intervention and therefore did not reflect the actual drop in the mean score for the RBMT at post-intervention. There was a slight increase in the standard deviation at post-intervention.

8. Family APGAR. Higher scores indicate greater satisfaction with family relationships. As the mean score at pre-intervention was a maximum of 10 (meaning individual participants had all obtained this score), there was no latitude for improvement at post-intervention. The mean score had dropped by only 0.5 at post-intervention. However, only two participants completed this measure at both pre-intervention and post-intervention and therefore scores are not representative of the whole sample.

9. BEHAVE-AD (Parts 1 and 2). Higher scores indicate the presence of greater psychiatric symptomatology. As can be seen, the mean scores obtained on Parts 1 and 2 were very low and zero respectively, meaning the degree of symptomatology

was minimal. However, there was a slight decrease in the mean score at post-intervention and the standard deviation and range were less.

10. Family Relations Question and Quality of Life Questions. Both these questions have rating scales with scores between 1 and 5 assigned to each response, with higher scores indicating greater satisfaction. As with other measures, mean scores on both were high at pre-intervention, meaning there was little scope for improvement at post-intervention. However, scores did not deteriorate. The standard deviation was slightly greater at pre-intervention than post-intervention for the Family Relations Question while for the Quality of Life Question the reverse was true.

Statistical analyses were carried out to compare scores obtained at pre-intervention and post-intervention scores on the following measures; RSE, GSES, HADS (Anxiety), HADS (Depression) and Rivermead Behavioural Memory Test (RBMT). It was not possible to carry out statistical analysis on any of the other measures due to insufficient participant numbers. As can be seen in Table 1, results confirm the descriptive statistics. There were no significant differences in scores obtained on any of the measures between pre-intervention and post-intervention. Anxiety did increase slightly from pre-intervention to post-intervention, but this was not significant.

Therefore, the primary hypothesis, that the intervention will lead to significant improvements in negative mood states associated with dementia, is not supported.

One of the secondary hypotheses was that there would be significant improvements in self-esteem, self-efficacy, family functioning, quality of life, psychiatric symptoms and perceived and actual memory functioning of people with dementia following the intervention. This could only be tested for those measures for which statistical analysis were carried out, namely self-esteem and self-efficacy. Results did not support the hypothesis. The mean scores that were calculated for the other measures also did not indicate support for the hypothesis.

b) Partner measures

Due to insufficient participant numbers, statistical analysis could not be performed to compare scores at pre-intervention and post-intervention. Therefore none of the hypotheses could be formally tested. However, mean scores, standard deviations and ranges were calculated for each measure, the results of which are displayed in Table

2.

Table 2. Means, standard deviations (SD), ranges and number of participants completing each measure for partners.

Measure (and range of scores)	Pre-intervention Mean SD Range Participants	Post-intervention Mean SD Range Participants	Follow-up Mean SD Range Participants
MARS (part of – Informant Version (Higher scores = higher reported memory))	22.25 8.54 13-30 n = 4	21.75 6.34 14-29 n = 4	NC
RMBPC Frequency (Lower scores = less reported problematic behaviours)	27.33 9.81 16-33 n= 3	24.33 2.08 22-26 n = 3	NC
RMBPC Reaction (Lower scores = less reported reaction to behaviours)	22.33 9.24 17-33 n = 3	15 2.65 13-18 n = 3	NC
RSE (10-40) (Lower scores = higher self-esteem)	24.75 4.36 22-30 n= 4	24.25 3.46 21-27 n = 4	NC
GSES (10-40) (Higher scores = higher self-efficacy)	32.25 5.56 27-38 n = 4	34.25 5.74 26-39 n = 4	NC
HADS Anxiety Scale (0-21) (Lower scores = lower anxiety)	8.67 3.51 5-12 n = 4	9.33 4.04 5-13 n = 4	NC

Measure (and range of scores)	Pre-intervention Mean SD Range Participants	Post-intervention Mean SD Range Participants	Follow-up Mean SD Range Participants
HADS Depression Scale (0 –21) (Lower scores = lower depression)	3.25 3.86 1-9 n = 4	4.25 2.87 1-8 n = 4	NC
Family APGAR (0-10) (Higher scores = better family relationships)	10 (score from 1 participant only)	10 (score from 1 participant only)	NC
Family Relations Question (1-5) (Higher scores = better satisfaction)	5 0 5 n = 3	5 0 5 n = 3	5 0 5 n = 3
Quality of Life Question (1-5) (Higher scores = greater satisfaction)	2.67 1.53 1-4 n = 3	3.67 0.58 3-4 n = 3	3 1 2-4 n = 3

There were no notable differences between scores at pre-intervention and post-intervention, although none deteriorated.

The measures are considered in turn:

1. Rosenberg Self-Esteem Scale (RSE). As with results obtained for people with dementia, mean scores and ranges were similar at pre-intervention and post-intervention. The standard deviation was slightly higher at pre-intervention. Lower scores indicate higher levels of self-esteem and as also found for people with dementia, mean scores were significantly lower (i.e. self-esteem was higher) than the mean score calculated for the general population (35.01), even when taking the

standard deviation into account, which indicates there was little latitude for change in a positive direction.

2. Generalised Self-Efficacy Scale (GSES). Mean scores, standard deviations and ranges were similar at pre-intervention and post-intervention, with the mean scores increasing only slightly at post-intervention. Higher scores indicate greater self-efficacy, and the scores tended to be greater than those calculated for the general population (29.28) taking the standard deviation scores into account.

3. Hospital Anxiety and Depression Scale (HADS), Anxiety Scale. Mean scores and ranges were similar at pre-intervention and post-intervention and were within the range that indicates the presence of possible anxiety. The standard deviation was slightly greater at post-intervention.

4. Hospital Anxiety and Depression Scale (HADS), Depression Scale. The mean score rose only by one point from pre-intervention to post-intervention and both scores were within the normal range. The standard deviation was slightly greater at post-intervention.

5. Family APGAR. Scores were available from one participant only and therefore the means, standard deviations and ranges could not be calculated. The participant obtained the maximum score at pre-intervention and post-intervention.

6. Family Relations Question. Higher scores indicate greater satisfaction. At pre-intervention, the mean score was the maximum it was possible to obtain (therefore all participants had given the highest possible rating) and the mean remained at this

level at post-intervention and at follow-up. As all individual scores were zero, the standard deviation at pre-intervention and post-intervention was zero.

7. Quality of Life Question. The mean score increased slightly from pre-intervention to post-intervention indicating more positive ratings of perceived quality of life and fell slightly at follow-up. The standard deviation and range were greater at pre-intervention.

8. MARS (Memory Performance Scale) -Informant Version. Mean scores were similar at pre-intervention and post-intervention. The standard deviation was slightly greater at pre-intervention. There was a large range of scores at both points in time, representing a high degree of individual variability.

9. The Revised Memory and Behaviour Problem Checklist (RMBPC), which is divided into two sections; behaviours of people with dementia as reported by partners and partners' reaction to them. The mean score for frequency of problematic behaviours was slightly lower at post-intervention. The standard deviation and range of scores were notably less at post-intervention. The mean score for partners' reaction to behaviours decreased notably at post-intervention and again the standard deviation and range of scores were less.

As it was not possible to carry statistical analysis out on the partner measures, the hypotheses relating to these could not be formally tested, although the results do not provide support for the hypotheses that there will be significant improvements in measures of self-esteem, self-efficacy, mood, family functioning and quality of life for partners of people with dementia following the intervention, or that partners will

report significant improvements in memory scores of people with dementia following the intervention, or that partners will report significant improvements in problematic behaviours displayed by the people with dementia and their (partners') reaction to them following the intervention.

c) People with dementia with partners versus people with dementia living by themselves.

Scores were explored to determine whether there were any differences between people with dementia living alone and people with dementia living with partners. Due to the insufficient participant numbers, this could not be tested using statistical analysis. However, the mean scores, standard deviations and ranges were calculated at pre-intervention and post-intervention. Due to the fact some of the measures were reviewed for Group C, only those that had been administered to all three groups could be considered for comparison purposes.

There were differences in some of the mean scores obtained by people with dementia living with themselves and those living with partners. The mean scores and ranges obtained are shown in Table 3. Each measure is considered in turn below.

Table 3. Means, standard deviations (SD) and ranges for people with dementia living with partners (in italics) and people with dementia living by themselves pre-intervention (pre) and post-intervention (post) with range of scores on each test in brackets.

For RBMT, SFS = standardised profile scores and SCS = screening scores.

Measure	Mean Pre	Mean Post	SD Pre	SD Post	Range Pre	Range Post
RSE (10-40)	<i>21.5</i> 21.67	<i>21.5</i> 21.67	<i>3.54</i> 1.53	<i>0.71</i> 0.58	<i>19-24</i> 20-23	<i>21-22</i> 21-22
GSES (10-40)	<i>33.67</i> 29	<i>32.67</i> 28	<i>4.93</i> 1	<i>2.52</i> 1	<i>28-37</i> 28-30	<i>30-35</i> 27-29
HADS – Anxiety (0-21)	5 8	8 8.67	<i>1.83</i> 4.36	<i>3.65</i> 4.16	<i>3-7</i> 3-11	<i>4-12</i> 4-12
HADS – Depression a (0-21)	3 3.33	3 4	<i>2.94</i> 4.16	<i>2.58</i> 4.36	<i>0-7</i> 0-8	<i>0-6</i> 1-9
RBMT – SPS (0-24)	5 10	2.5 10	<i>4.24</i> 8.19	<i>0.707</i> 8.54	<i>2-8</i> 3-19	<i>2-3</i> 2-19

1. Rosenberg Self-Efficacy Scale (RSE). There were no notable differences in mean scores obtained by people with dementia living by themselves and those living with partners. The standard deviation was greater for people with dementia living with partners at pre-intervention but scores were similar for both groups at post-intervention. The ranges were greater for both groups at pre-intervention than post-intervention.

2. Generalised Self-Efficacy Scale (GSES). The mean scores were slightly lower (indicating lower levels of self-esteem) for people with dementia living by themselves. However, scores for both groups remained stable at pre-intervention and

post-intervention. The standard deviation was notably higher for people with dementia living with partners, particularly at pre-intervention.

3. Hospital Anxiety and Depression Scale (HADS), Anxiety Scale. The mean score for anxiety rose at post-intervention for people with dementia living by themselves from within the normal range to within the range indicating possible anxiety. For people with dementia living with partners, the scores remained similar at both times of testing. The mean score for people with dementia living with partners was in the range indicating possible anxiety at pre-intervention and therefore the mean score for people with dementia living by themselves rose to the level the former group had been at initially. The standard deviation and ranges were greater for people with dementia living with partners at both pre-intervention and post-intervention.

4. Hospital Anxiety and Depression Scale (HADS), Depression Scale. Mean scores obtained by people with dementia living by themselves and those living with partners were similar, but the range was greater at post-intervention for people with dementia living by themselves. The standard deviation was greater at both pre-intervention and post-intervention for people with dementia living by themselves.

5. The mean standardised profile scores of the Rivermead Behavioural Memory Test (RBMT) fell for the people with dementia living with partners but remained constant for people with dementia living by themselves. The standard deviation was substantially greater for people with dementia living by themselves for both sets of scores.

It was not possible to formally test the hypothesis that people with dementia living with partners will perform significantly better on measures than people with dementia living by themselves, but results indicated this was not supported.

d) Maintenance of positive effects at follow-up.

The final hypothesis was that any positive effects would be maintained at follow-up. It was not possible to test this hypothesis due to the fact that scores did not improve overall on measures at post-intervention. Also, it was not possible to administer the majority of measures at follow-up. From those measures that were completed at follow-up, (the Family Relations and Quality of Life Questions) the mean scores were similar at follow-up to those obtained at pre-intervention and post-intervention for both people with dementia and their partners.

e) Discrepancy between ratings of people with dementia of their memory abilities and their partners' ratings.

The discrepancies between ratings of the memory ability by the people with dementias' themselves and their partners were also considered. Tables 4 and 5 show the individual scores obtained by the people with dementia on the MARS Self-Report Version and Performance Scale respectively.

Table 4

	Pre	Post	FU
1a	44	37	38
2a	43	35	46
3a	37	40	38
4a	NC	45	NC
5a	32	NC	NC
6a	35	NC	NC
7a	44	39	NC
8a	46	39	NC
9a	38	38	NC

NC = Not completed

Table 5

	Pre	Post	FU
1a	34	36	32
2a	22	23	28
3a	NC	NC	NC
4a	37	28	NC
5a	33	NC	NC
6a	NC	NC	NC
7a	34	34	NC
8a	17	9	NC
9a	41	37	NC

NC= Not Completed

Table 6 shows the individual scores obtained by partners on the MARS Informant

Version.

	Pre	Post	FU
1b	29	14	14
2b	13	24	28
3b	17	20	19
4b	25	29	NC

As there were a number of measures not completed, discrepancy scores could not be calculated for a number of participants. However, a general overview of the tables showed notable discrepancies between the reports from people with dementia regarding how well they felt able to perform and their actual performance

(participants overestimated how well they thought they could perform in various tasks) and between how well the people with dementia thought they could perform in the tasks and how well their partners thought they could perform (partners' ratings were much lower).

2. Individual results

The small sample size meant that statistical power was low. It is likely that the findings reflect individual variability. Therefore, it was decided to look at results on a single case basis.

Table 7 show the descriptive data for people with dementia. All participants had a primary diagnosis of Alzheimer's Disease.

Participant no.	Age	Gender (M = male, F= female)	Has partner	Anti-dementia drug
1a	73	M	Yes	Donepezil
2a	76	F	Yes	Donepezil
3a	70	F	Yes	Donepezil
4a	79	F	Yes	Donepezil
5a	80	F	No	Donepezil
6a	80	F	No	None
7a	80	F	No	None
8a	75	F	No	Rivastigmine
9a	76	F	No	None

As can be seen, the age-range for people with dementia was 10 years, all but one was female, 6 out of 9 were taking an anti-dementia drug and 4 out of 9 had partners.

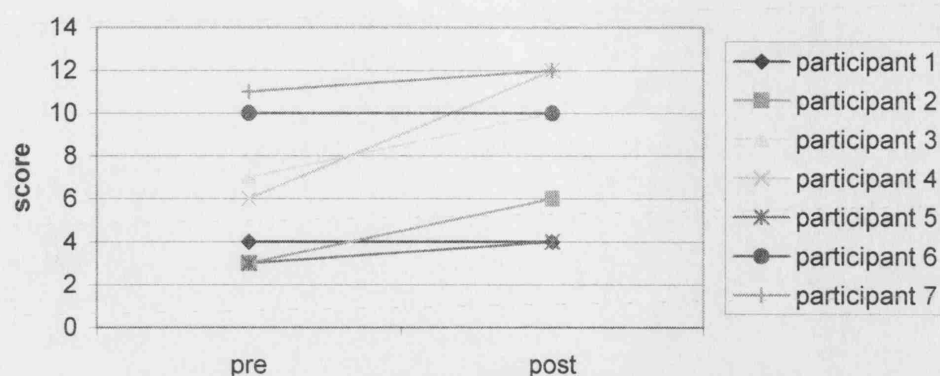
Table 8 shows descriptive information for partners of people with dementia.

Partner no	Age	Gender (M = male. F = female)
1b	70	F
2b	73	M
3b	72	M
4b	79	M

The age range for partners was 9 years and 3 out of 4 were male.

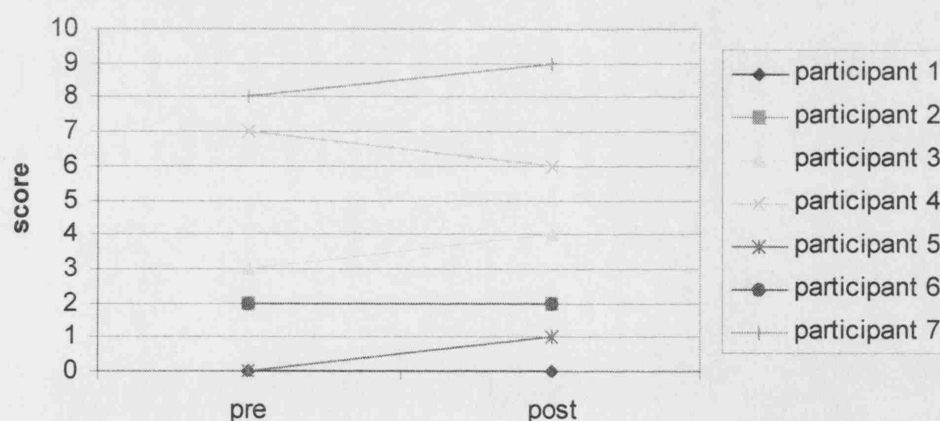
The individual variability on various measures is now discussed. The following graphs are for measures for people with dementia on which statistical analysis was carried out. Measures were not completed at pre-intervention and post-intervention for all participants and only those participants for whom measures were completed at both points in time are shown. As only a small number of participants completed measures at follow-up these scores are not shown.

Graph 1 showing individual anxiety scores on Hospital Anxiety and Depression Scale

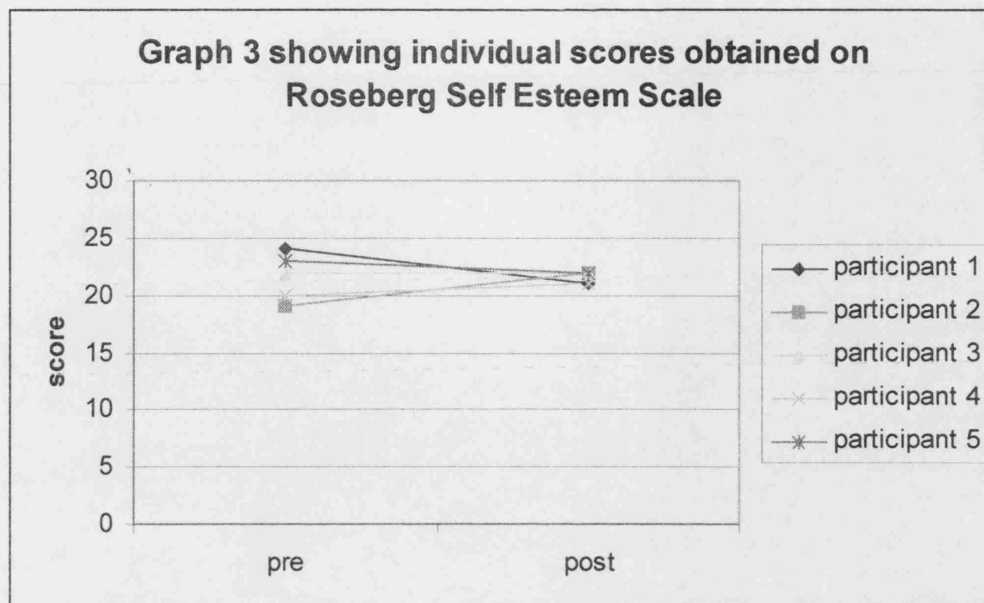


As the graph shows there was a tendency for individual scores to increase although only by a few points with the exception of one participant whose score increased by 6 points. Participants 1 to 4 had partners and the others were living by themselves.

Graph 2 showing individual depression scores on Hospital Anxiety and Depression Scale

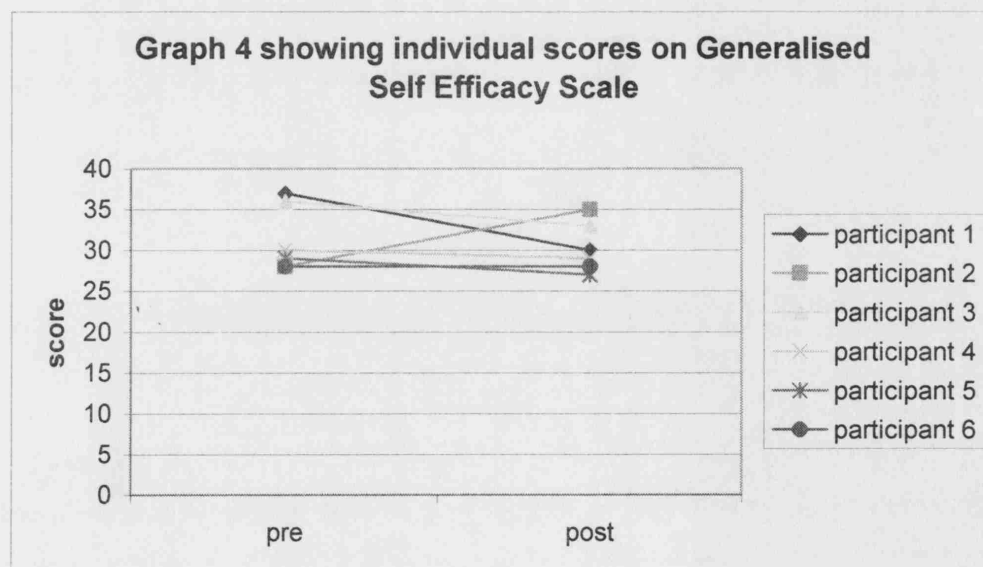


As the graph shows scores of 2 participants remained the same at pre and post intervention, one participant's score decreased and the scores of the remaining participants increase slightly. Participants 1 to 4 had partners, the rest were living on their own.



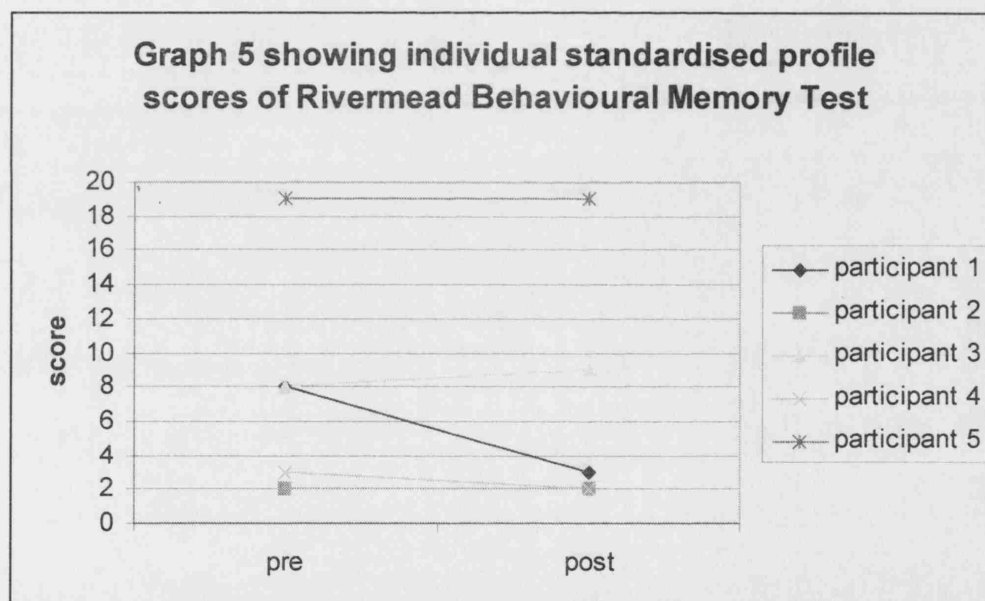
As the graph shows there was little variance between scores of all participants at pre and post intervention with some increasing and some decreasing slightly.

Participants 1 and 2 had partners and the others were living by themselves.

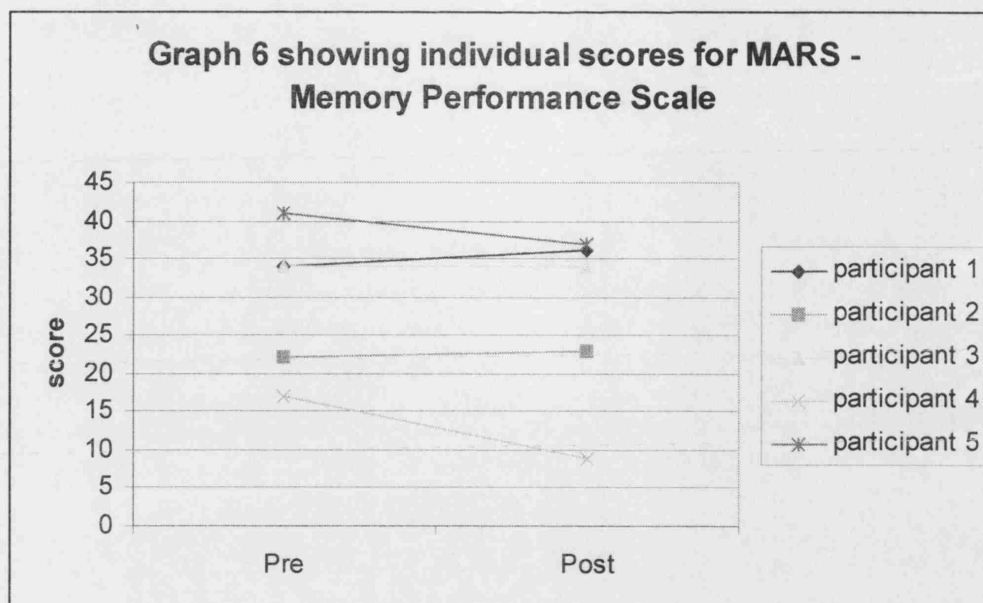


As the graph shows there was little variance between participant scores at pre and post intervention. Participants 1 to 3 had partners, the others were living by themselves.

The only mean score for people with dementia that fell notably from pre-intervention to post-intervention was the Revised Behavioural Memory Test; however as the graph below shows this was mainly attributable to one participant. As the graph also shows, there was a wide variation in scores with one participant obtaining a score of 19 and another a score of 2. Participants 1 and 2 had partners, the rest were living on their own.



Although the main score for the Memory Performance Scale fell only slightly, as the graph overleaf shows the individual score for participant 4 fell notably from pre-intervention to post-intervention. Participants 1 and 2 had partners, the reminder were living on their own.



3. Case Audit

Table 9 below shows the results of the case audit, which was carried out as a result of the low number of referrals to identify how many people would have been eligible for the study. The table below shows the number of people that did and did not meet the inclusion criteria, followed by a breakdown of the reasons that people did not meet the criteria. These are not mutually exclusive as in some cases people with dementia did not meet two or more of the inclusion criteria. The audit took place over a period of 3 months and consisted of a convenience sample.

Table 9

No of people meeting inclusion criteria	No. of people not meeting inclusion criteria	No. not having had diagnostic disclosure	No. not having MMSE score of 18 or above	No. with medical conditions currently being investigated or assessed	No. with visual or hearing problems
5	20	16	7	3	3

It was not possible to verify one of the inclusion criteria, whether people were able to give informed consent, from the notes and neither was it possible to verify two additional criteria that were considered, namely that there was a person independent of the Trust able to be a witness to signing the consent form and the person accepted that (s)he had a memory problem and would be willing to discuss issues relating to this in a group situation. This means that these 5 cases that were identified as meeting the inclusion criteria may not, in fact, have been suitable for the study.

Although 16 people did not have diagnostic disclosure according to the notes, it was recognised that this information may not have been documented. These results provide some indication as to why it was difficult to recruit people from the service that met the inclusion criteria, and demonstrate that recruitment difficulties did not arise because potentially suitable participants were being missed.

4. Qualitative information

This information from the reflective journal and subjective measures and satisfaction questionnaires completed by Group C is considered.

a) Reflective journal

Information about the initial interviews and the groups were recorded. The main points were:

- During the initial interviews to discuss the groups with partners and people with dementia, ideally two members of staff would have visited in order to carry out separate interviews. In practical terms this was not possible, which created difficulties as the partner was often interested in participating but the person with dementia was not.
- The Family APGAR was used in the first stage of the feasibility study but feedback from participants was that the questions were not applicable. The measures asks about social support and it was used for people with dementia living on their own whom in some cases had no family living nearby.
- Some of the people with dementia found the Rosenberg Self Esteem Scale and Generalised Self Efficacy Scale difficult to complete. Comments included indications that the questions were too general or were more relevant to people who were still in the work place.
- One of the people with dementia spontaneously stated that she had enjoyed the interviews during which the measures had been carried out and felt that the time that the Research Psychologist (myself) had spent

with her building up rapport had been beneficial in terms of completing the measures.

- The same participant stated that she had learnt techniques from the groups even if they had not seemed useful at the time.
- The initial session for people with dementia seemed to work well, with participants contributing to the discussion, but the other three sessions on memory techniques and strategies went less well.
- In the partners' group, participants spent more time talking about the different points, meaning that it was difficult to cover the same amount of material in the time-period. The social part of the group, in terms of sharing ideas and experiences and offering each other advice, worked much better for partners.
- In the group for people with dementia, participants found it difficult to generate examples of memory aids they were already using and did not generally feel that there were any it might be useful to start using. They found it difficult to generate examples, even with support, of any situations they found particularly hard to remember information in.
- Group exercises worked well for the partners' group but not for people with dementia. Even though these were done informally, on a group as opposed to on an individual basis and it was emphasised that participants did not have to take part, people with dementia seemed uncomfortable with the concept of this.
- Partners questioned why they and the people with dementia had been divided into two groups, even though this had been explained prior to the intervention.

- Partners reported that people with dementia did not discuss the courses at home.
- Probably as a result of the above, partners asked what was covered in the group for people with dementia, even though it had been explained prior to the intervention that the same topics would be covered and this was reinforced by the fact that handouts for people with dementia and their partners were very similar.
- General feedback from the groups was that participants had found it beneficial to meet with others and that they had been given the opportunity to discuss issues that they wanted to.
- Two further social groups were held at the request of both people with dementia and their partners. These were joint sessions for people with dementia and their partners and although the group facilitators were present there was no formal structure. These sessions seemed valued by both people with dementia and their partners. Participants discussed a range of issues, for example reminiscing about when they first been married, moving on to dementia at the end of the session. One person with dementia said that he had felt stupid when first told he had dementia and also felt this way when he did not recognise people. Another person with dementia stated that she did not feel embarrassed.
- Two couples exchanged telephone numbers with a view to meeting up afterwards.

b) Results from subjective measures

Another research question that was considered was whether participants gave positive reports of the intervention. Results from qualitative measures are considered. Group C were asked about goals relating to their partners and their own memory. One of the partners wrote a letter following the intervention that included his views about the course (which were encouraging) and issues relating to the National Health Service in general. Prior to the intervention, two participants with dementia identified general goals (to help with conversation and control temper). One participant with dementia was unable to identify any goals. One partner stated he would like the person with dementia to be more able to concentrate.

After the intervention, participants were asked whether they felt any identified goals had been met. One participant with dementia said the group had been comfortable, friendly and helpful. Another participant with dementia identified a memory technique (putting things in the same place) she had started using as a result of the course. Partners were able to identify techniques they had learnt from the course (using a diary more and moving away from difficult situations as opposed to confronting them when this was likely to make things worse). One partner said he was already using some of the memory techniques discussed and had tried to introduce new ones, but his partner (his wife) did not feel happy with these.

At follow-up, one of the participants with dementia said it had been useful to meet the other participants. One partner said that the most useful element of the course had been meeting others in a similar situation as opposed to learning about techniques to help with memory. The other two partners said they had already been

using memory techniques prior to the course. One suggestion was that future courses could be run for people with dementia and their partners jointly or offered to partners only. It was also suggested that techniques for coping with difficult situations could be covered in more depth.

In summary, the overriding message seemed to be that meeting other people in a similar situation and sharing ideas had been useful. Although some of the memory techniques covered seemed to be of some value, it appeared that participants were already aware of and implementing the majority of them.

c) Satisfaction Questionnaires

All three couples from Group C completed satisfaction questionnaires about the course. All provided a response about what they had found most useful. Comments were fairly general in nature, for example 'all the ideas covered were useful' or 'ideas for memory aids'. Nobody said they felt there was anything that had not been useful.

In response to whether anything could be changed in future courses, suggestions were 'a slightly larger group' or 'information about how to cope with daily routines if they changed in the future'. One person said the greatest help from the course had been 'to meet and share information with others in a similar situation' and 'discuss personal experiences'. One suggestion was that handouts should be sent out in the week prior to when each topic was to be covered to provide participants with the opportunity to look at them before the session, as opposed to handing them out in the actual session. It was also suggested that it may be more useful to run the course for people with dementia and partners jointly or run it for partners only.

Summary

With regards to the overall research question, namely to evaluate the feasibility and efficacy of the intervention, there is support for some aspects of this but not others.

a) Feasibility of the intervention

The group format seemed feasible, relevant and workable for partners but less so for people with dementia. The main problems affecting the feasibility of the study were difficulties in recruiting, a lack of people with dementia meeting the inclusion criteria, the issue of people with dementia not understanding the concept of research and therefore not being able to be included because of issues of informed consent and people with dementia not wanting to participate in a group intervention. The difficulties in recruiting resulted in the group numbers being smaller than ideal.

As the partners took part far more in the group discussions, the intervention seemed far more acceptable and relevant for them. Although partners reported that they were already familiar with the memory aids that were discussed, they said that they found it reassuring to know that they were using the same techniques as others. The sessions on memory techniques and strategies worked less well for the people with dementia although they did seem to benefit from and enjoy the sessions on feelings and memory and coping in social situations.

b) Efficacy of the intervention.

There were no significant differences on objective measures addressing self-esteem, self-efficacy, anxiety and depression for people with dementia at pre-intervention

and post-intervention. However, self-esteem, self-efficacy, anxiety and depression were within normal limits prior to the intervention meaning there was little scope for improvement. Levels of behaviour problems reported using the BEHAVE-AD were also low initially, meaning there was also little scope for improvement. Anxiety did increase although this did not reach significance.

Due to low participant numbers, it was not possible to carry out statistical analysis on measures for partners. Mean scores on the Revised Memory and Behaviour Problem Checklist showed a slight drop in frequency of problematic behaviours reported from pre-intervention to post-intervention and a substantial drop in reaction to behaviours. This seemed to be the result of individual variance and a larger sample would be required to verify whether this could be attributed towards the intervention. There were no notable differences between other mean scores obtained by participants on any of the measures. As for the people with dementia, scores of self-esteem, self-efficacy, anxiety and depression were within normal limits initially, meaning there was little scope for improvement.

However, qualitative reports were encouraging with participants seeming to value the experience of meeting and gaining support from others in a similar situation and having the opportunity to share ideas. This seemed more valuable than the more practical advice about memory aids, which participants seemed to be familiar with prior to the course. The difficulty of reliance on subjective measures is that participants may feel that they should provide positive reports regarding an intervention, although the fact that both people with dementia and partners chose to meet on two occasions socially afterwards indicates that they did find meeting others

served a supportive function.

Chapter 4

Discussion

Overview

In terms of the overall research question to evaluate the feasibility and efficacy of the intervention, support for this was limited and there are issues that would need to be addressed for future studies. The intervention seemed far more relevant and workable in practice for partners of people with dementia, although the latter did seem to value the sessions involving a CBT component. This differs from the cognitive stimulation programme described by Spector et al. (2003) in which participants significantly improved on cognition and quality of life following the intervention. However, although the aim was that the current intervention would involve practicing tasks this did not occur in reality and it may be that this would be required for any changes on these types of measures. Clare, Wilson, Carter, Breen, Berrios and Hodges (2002) state that cognitive rehabilitation is an individualised approach and therefore within subjects or single-case designs are often adopted for this approach. Clearly the cognitive rehabilitation component did not seem to work on a group basis.

The intervention did not seem valued by the people with dementia to the same extent as the support group described by Pratt et al. (2005) but this differed in that it had the focus of being a support group as opposed to comprising other types of intervention and it was also an open group, with people being able to join or leave at any time. Partners seemed much more keen on the group than people with dementia and even though it was emphasised to couples that the partners could attend even if the person with dementia did not wish to, in reality it may be that partners had an

influence on the attendance of the people with dementia. Clare (2003) states the need for a holistic approach in which cognitive, emotional and motivational factors are all taken into account within the context of the situation. Keady, Woods, Hahn and Hill (2004) describe an intervention that attempted to identify the meaning and context of interventions for people with dementia, which also highlights the importance of taking a range of underlying issues into account when planning an intervention. It is unlikely that the current intervention adequately accounted for all these factors. In a psychotherapeutic group described by Cheston, Jones and Gilleard (2003) there was a significant reduction in depression and reduction in anxiety that was close to significance, which supports the efficacy of this type of intervention. However, it is worth noting that although anxiety and depression scores fell on the Cornell Scale for Depression and Rating Scale for Dementia, this was not reflected by scores obtained on the Hospital Anxiety and Depression Scale, which highlights the fact the inconsistencies that can be found between different measures and emphasises the importance of selecting sensitive measures to measure the efficacy of an intervention. Therefore, future interventions should take inclusion criteria, content of intervention, interaction between factors, situational context and relevance of measures into account to a much greater extent.

Findings showed an increase in anxiety following the intervention for people with dementia, although this did not reach significance. This is in line with the observation that interventions involving memory training may have negative effects on the well-being of both people with dementia and their carers as pointed out by Clare (2003), although Spector et al. (2003) showed significant improvements in both cognition and quality of life following the cognitive stimulation programme for people with dementia. However, in the current study, when individual scores were

considered, 2 participants did not complete the Hospital Anxiety and Depression Scale at post-intervention, 2 stayed the same at pre-intervention and post-intervention and a further 2 rose by only one point. The increased trend seemed to result from the scores of 3 participants only, of who 2 had scores that rose by 3 points, and one had a score that rose by 6 points. Clearly in a small sample overall findings are affected by individual variance and the fact that one participant rose by 6 points could be attributed to a number of factors other than the intervention. Unfortunately, as this was the first stage of the feasibility study, this information is not available. The finding that some participants increased in anxiety highlights the importance of considering the inclusion criteria for this type of intervention carefully in terms of who might benefit from the intervention and who might not. The fact that individual differences might be masked by group results was demonstrated by the study by Zarit et al. (1987), in which significant changes were not found. However, when it was reanalysed by Whitlach, Zarit and Von Eye (1991) using a technique to take individual differences into account significant differences were found.

Due to small participant numbers, it was not possible to carry out statistical analysis on the Rivermead Behavioural Memory Test, but mean scores showed a substantial drop from pre-intervention to post-intervention. However, this was also affected by individual variance. From the 5 participants who completed the measure at both pre-intervention and post-intervention, 1 person increased by 1 point, 1 decreased by 1 point, 2 stayed the same and the score for the remaining participant fell by 5 points. An individual breakdown of scores in other studies, for example Ishizaki et al. (2000), shows how the overall result does not always present a realistic picture of individual variability. In the current study, without the participant whose score dropped notably, there would have been no substantial difference between scores on

the RMBT at pre-intervention and post-intervention. On the basis of the fact that cognitive abilities of people with dementia would be expected to decline over time, other studies (for example, Quayhagen and Quayhagen 1989) have interpreted the finding that cognitive scores have remained stable as meaning that the intervention was successful, although arguably in the short time frame of the current study a decline would not be expected.

There was a slight drop in mean score from pre-intervention to post-intervention on the Revised Memory and Behavioural Problem Checklist in terms of behaviours reported by partners and a substantial drop in report of reaction to behaviours. Data was only collected for 3 partners at both pre-intervention and post-intervention and this result is largely a result of variance of one participant. This once again highlights the issue of individual differences and that an intervention may be useful for some participants but not others. Another factor was that for many measures, scores at pre-intervention were within normal limits at pre-intervention, meaning there was little scope for improvement. For example, self-esteem and self-efficacy were higher than norms calculated for the general population. Similarly, anxiety and depression were within the normal range prior to the intervention and degree of behavioural and psychiatric symptoms as reported by the BEHAVE-AD were low. This highlights the importance of selecting relevant, sensitive measures that may detect change.

One of the main reasons for providing a group as opposed to an individual intervention was the support that it provided by meeting others in a similar situation (Yale, 1995). This was borne out by group observations of the partners, reports from participants and also the fact that people with dementia and partners from Group C

requested two social meetings following the intervention. However, it is important to take into account that a group intervention is unlikely to be suitable for all people along similar lines to Cheston, Jones and Gilleard (2003) who stated that their psychotherapy groups might not be suitable for everybody.

As reported, partners seemed to value the intervention far more than the people with dementia. This may be why the most successful outcomes seemed to be associated with Group C, as Group A involved people with dementia only and Group B involved only one partner for whom measures were carried out (the other partner in the group did not wish to participate in the research component and therefore measures were not completed for him). Furthermore, whereas the two partners in Group B discussed a wide range of issues, many of which were not applicable to the intervention, partners in Group C seemed far more focused on the task in hand. Partners in Group C also seemed in similar stages with regards to using memory aids and techniques, although one partner did comment that her husband seemed to have an earlier stage of dementia than the other two people in Group C. Another reason why Group C was more successful was that this was the second stage of the feasibility study and the protocol and session content had been revised. The material was essentially the same but components that had worked less well were dropped for this phase. In addition, Group B consisted of only two people with dementia and two partners, meaning there were two participants and two facilitators in each of the parallel sessions, which was not ideal. Group C had 3 people with dementia and 3 partners, this being slightly better but not a larger number of participants would have been better. Group A was best in terms of numbers; there were 6 people with dementia although one dropped out of the intervention. Drees et al^{ab}. (2004) showed that support involving both people with dementia and caregivers was superior to that

involving only the person with dementia but the results from the current study demonstrates the need to select people with dementia who are motivated to carry out the intervention.

Problems in recruiting arose from a) a lack of referrals and b) people, in particular those with dementia, not wanting to participate. These are considered in turn.

Referrals from the first stage of the feasibility study were from the Psychology Department but due to staff shortages professionals outside the department were asked to refer people for the second phase of the study. There was a problem with lack of referrals in general, probably because research was not a routine part of the service. In many cases people did not meet the inclusion criteria, mainly because of not having had diagnostic disclosure, as is also supported by the case audit. One of the psychiatrists referred a number of people but as he did not routinely give people their diagnosis, they could not be included in the intervention. Without diagnostic disclosure, it would not have been possible to work through some of the issues raised in the sessions. There would also have been the danger of participants finding out about their diagnosis by accident; in Group C people with dementia openly discussed their diagnoses during the first session. Another problem was that people were referred who had MMSE scores below 18, which might have been a result of the service not being tailored towards research and clinicians not understanding the implications of this.

With regards to people not wanting to participate, when couples were visited to carry out the initial interviews, partners generally seemed interested in participating but people with dementia did not. In some cases, the partner tried to encourage the person with dementia to take part and the interviewer (myself) had to intervene as

clearly it would not have been ethical for the person with dementia to take part in the intervention if he/she did not want to. Ideally, two people would have visited the couple to carry out the initial interview, one to discuss the intervention with the person with dementia and one the partner to avoid this type of situation, but this was not possible due to low staffing levels in the service. It is understandable that people with dementia may not like the idea of meeting new people and participating in a group situation at a time when they are coping with the diagnosis of dementia and are having difficulties with processing new information. There were no differences resulting from whether the intervention was referred to as a group or course (it had been thought that people might feel more comfortable with the latter). It would be worthwhile considering offering interventions for partners only, for cases in which people with dementia choose not to participate. Unfortunately, this was not a viable option in the context of the present study, because it would not have worked in the context of the research framework. The initial interview to discuss the intervention was also not prioritised by many participants, with social activities often being placed before it in importance. Another difficulty with recruitment was that the majority of potential participants were not familiar with the idea of research. It is unlikely they would previously have been approached by anyone in the Trust regarding participation in a research project and some people found this a difficult concept to grasp. In particular, people seemed to feel because it was a research project it would be not be of benefit to them, even though it was explained that the Research Psychologist hoped it might be of some use. Ideally, other professionals involved in the care of the person with dementia initially explained what the intervention involved, that it was part of a research project and why it might be beneficial. However, this was not always the case and the Research Psychologist, who was not known to potential participants, had to explain these points in many

cases. As it was felt it would not be fair to visit people at home without first outlining the research component, in a number of cases the Research Psychologist had to mention this over the telephone, which was not ideal. Another reason for people not wanting to participate was not valuing a psychological as opposed to a pharmacological intervention.

The intervention was targeted at people with early stage dementia and this was deemed to be people who had a score of 18 or above on the Standardised Mini Mental State Examination, as this measure was used by the psychiatrists on a routine basis and therefore was available for all potential participants. However, this is an unsophisticated measure and ideally a more sensitive measure would have been used. In addition, observations from the group highlighted the need to take other factors besides cognitive ability of people with dementia into account, for example degree of insight, whether defence mechanisms are being used, whether people feel comfortable and able to discuss their memory difficulties, particularly in a group situation, and whether they are motivated to try using memory techniques and strategies. One participant with dementia did not feel comfortable in completing the Rivermead Behavioural Memory Test (which was not carried out), probably because it drew attention to her cognitive deficits. This same person did not seem to enjoy the cognitive rehabilitation and psychoeducational aspects of the intervention, which was likely to be for the same reason (her partner seemed to find the sessions very valuable, but it was emphasised to both of them that the person with dementia did not have to attend future sessions if she did not wish to). However, the person with dementia seemed far happier with the sessions involving a CBT component, an observation that was confirmed by her partner and she also seemed to value and enjoy the social sessions that were run after the intervention.

The time frame for the intervention was fairly short at 7 weeks and although this seemed adequate for partners, a longer time frame might have been more beneficial for people with dementia who seemed to take longer to adjust to the group setting, although this was probably a result of the content of the intervention. Although the reason that people with dementia seemed more comfortable with later sessions was deemed to be a result of the component of the intervention, namely CBT, an alternative explanation may be that as these sessions were later on in the intervention participants had had time to adjust to being in a group situation. It is difficult to make a recommendation on length of intervention for people with dementia, given that the cognitive rehabilitation and psychoeducational element of the intervention did not seem to be that successful for this group, but a slightly longer intervention, for example 2 months, would seem more appropriate. The groups described by Cheston et al. (2003) lasted for 10 weeks.

Providing an intervention to both people with dementia and their partners seemed to be positive, as this provided an opportunity for various issues to be addressed by the couples outside of the sessions (although this did not happen in practice in the current intervention). A number of interventions (see, for example, Keady et al. 2004) have provided interventions not only to the person with dementia but also the family. However, people with dementia might also have found it stigmatising if only their partners were offered an intervention that was targeted at issues around their illness and this would not take into account the needs of the people with dementia themselves, at least directly. Findings from the study must be regarded with caution as a result of small participant numbers. Future studies could also pay more attention to inclusion criteria in terms of defining early stage dementia more adequately and

taking other factors into account, for example whether people are motivated to use memory techniques.

Both people with dementia and partners were already familiar with many of the memory techniques discussed, and a future intervention could target people who have been more recently diagnosed and have not had the opportunity to explore these, although partners found it helpful to revisit these techniques because it reinforced that they were taking the right approach. One of the factors on which the implementation of memory techniques depends is prior level of knowledge, and as participants and partners in this study were already aware of and using a number of the memory aids discussed, only a limited amount of new knowledge was gained

In terms of efficacy of the intervention, there was no support for the primary hypothesis, namely that the intervention would lead to significant improvements in negative mood states associated with dementia. Other studies, for example Marriot *et al.* (2000) and Magni *et al.* (1995), have shown reductions in negative mood states such as depression or stress following the intervention, but in this case anxiety actually increased for some participants.

Due to insufficient data, it was not possible to carry out statistical analysis on some of the measures for people with dementia or any of those for partners and subsequently the secondary hypotheses could not all be tested. However, there were no significant changes on those that were tested, namely self-esteem, self-efficacy and depression.

There were encouraging qualitative findings in the form of positive reports by participants, in particular the partners of people with dementia. However, it is important to acknowledge that participants may feel they should provide positive feedback, particularly as the people carrying out the assessments were also the group facilitators. Certainly, the group facilitators' perception was that, although partners of people with dementia had valued the group, the people with dementia did generally not enjoy or benefit from it. However, the fact that both people with dementia and their partners from Group C requested that two social meetings could be held following the intervention and all members of the group contributed to the discussion in these suggested that people did find the supportive function of meeting others beneficial.

Future studies

In summary, results from this study suggested that partners valued all the components of the intervention but people with dementia only seemed to find the CBT component beneficial. This meant that partners would try to discuss issues arising from the cognitive rehabilitation and psychoeducational components at home but people with dementia did not want to. A future intervention for people with dementia could concentrate on CBT or have a primarily supportive function but the cognitive rehabilitation and psychoeducational components could either be removed or inclusion criteria for participants should be considered much more carefully.

The intervention should be provided to both people with dementia and their partners in view of the fact that this type of intervention seems to be associated with superior outcomes. However, it should follow the format of parallel rather than joint sessions as in the current study, with the rationale for this being the same. The intervention

should include a control group in order to control for therapist attention effects and participants should be randomly assigned to the intervention or control group.

Measures used to define early stage dementia should be more sensitive than the MMSE, which is a fairly blunt instrument. The primary outcome measure should be negative mood states as an intervention comprising CBT might be expected to target this aspect. Therefore one of the inclusion criteria should be that participants have clinical levels of anxiety or depression prior to the intervention. However, it would be useful to also incorporate subjective measures and observations, whilst accounting for the difficulties with these such as the fact that people are inclined to give positive reports. However, a wealth of useful data can be obtained from qualitative studies and this should be acknowledged. It would be useful to triangulate objective measures, subjective measures and group observations.

The fact that people shared their experiences is exemplified by Group C, during which people with dementia discussed their diagnoses in the first session. One participant discussed his feelings about having had his driving licence revoked as a result of his diagnosis, this clearly being a major issue for him. Although it has been put forward that people with dementia might have difficulty in interacting in a group basis as a result of their cognitive difficulties, people with dementia clearly had no difficulty in discussing these type of issues, which suggests that the problem was not that the intervention was a group one but that the content was not all relevant for this particular group of participants.

Satisfaction ratings are useful but must be regarded with caution since a number of studies have reported positive satisfaction ratings but no changes on objective

measures (for example, Brodaty et al., 1994). There is a tendency for people to give high reports of satisfaction. However, these are useful if used in conjunction with others' ratings, for example observations. The additional qualitative information collected in this study gave significant insights into the types of measures that people with dementia and their partners felt were not applicable and the group observations gave insights into what types of intervention people felt were relevant. In future studies, it would be helpful to combine this type of information with an objective measure, for example the Hospital Anxiety and Depression Scale, but to carefully select participants for whom anxiety or depression are at clinical levels initially in order that the intervention may have a benefit for people with regards to this.

The following sections consider some of the main quantitative and qualitative findings.

Quantitative findings

There are a number of possible reasons why there were no significant changes on measures in the current study. First, there were methodological limitations. The small sample size meant that statistical power was limited. Unfortunately, due to problems with recruitment, the number of participants was substantially lower than anticipated. This was exacerbated by the fact that there were a number of incomplete measures, often due to participants not feeling questions were relevant to them. For example, with the Rosenberg Self-esteem Scale and Generalised Self-efficacy Scale participants with dementia often felt the questions were only applicable to people in the work-place or were too general, and were unable to draw on examples (even with assistance) that would help them relate the questions to themselves. Both measures

consist of a choice of 4 responses and participants also found it hard to select one of these, even with assistance.

The lack of a control group was another methodological issue. As previously mentioned, the original intention had been to have a cross-over design, with support groups as a comparison condition, but for a number of practical reasons it was not possible to carry this out. Problems with methodology in past studies have been highlighted in reviews of various types of psychosocial interventions (e.g. Briggs and Thompson, 1998; Pusey and Richards, 2001; Spector et al., 2004a; Spector et al., 2004^b). In a study reported by Brodaty et al. (1994), the authors specifically drew attention to the lack of statistical power. These types of problems lead to difficulties in inferring how effective an intervention has been. The original design of the present study aimed to take past methodological problems into account, but it was not possible to carry it out for the reasons detailed in Appendix 2.

In terms of the cognitive rehabilitation component, other studies e.g. Clare et al. (1999, 2000, 2002) have demonstrated significant changes on targeted tasks using cognitive rehabilitation techniques specifically adapted for the individual.

Although specific techniques that participants could use were discussed in the current intervention, it was not possible to explore these issues in as much depth in a group situation and as mentioned people with dementia seemed reluctant to do this.

Therefore, an individualised approach focused more directly on individual goals would be more helpful.

The non-significant findings can also be considered in terms of the fact that it may take a while for information covered in interventions involving psychoeducation to be taken on board (Pusey & Richards, 2001). It was only possible to carry out

follow-up measures with three people with dementia and their partners and this was only done after three months. Although there were no overall changes, it is hard to draw firm conclusions from the small numbers involved.

Also important to consider is the fact that statistical analysis could not be carried out on all of the measures due to insufficient participant numbers. However, mean scores, standard deviations and ranges for pre-intervention and post-intervention were calculated for all measures. Mean scores for some of these measures (i.e. Family Functioning Question, Quality of Life Question) did not show any notable changes. The importance of carrying out follow-up assessments, as discussed above, is exemplified by the results obtained by one of the partners on this measure.

Although the score for ability to deal with behaviours improved slightly from pre-intervention to post-intervention, it improved substantially at follow-up. Lack of awareness of impairments can be associated with dementia and this was assessed by the Memory Functioning Scale, Self-Report Version and Memory Performance Scale, both used with people with dementia. Also of interest is whether there are differences between ratings obtained by people with dementia and those of their partners, the latter being assessed by the Memory Functioning Scale, Informant Rating Scale.

The disparity in scores between participant and caregiver ratings might be taken to indicate that the people with dementia had limited insight into their difficulties. This has implications when planning interventions. Although one of the inclusion criteria was that people had awareness of their memory difficulties, this is not clear-cut as awareness can vary from one situation to another, for example who is asking a question and how it is asked may make a large difference to the response. However,

results on the Memory Performance Scale suggested that participants had more awareness of the extent of their difficulties for tasks than they had for hypothetical situations. There are a number of possible explanations for this. It may have been due to difficulties in processing (hypothetical situations are likely to be harder to visualise). Questions from the Memory Performance Scale relate to sections of the Rivermead Behavioural Memory Test and carrying out the latter may have increased participants awareness of their memory problems. If people are using denial as a defence mechanism, this becomes less easy if they are performing poorly on tests. This suggests that people with dementia may have more insight into their memory difficulties than may be initially apparent. Reluctance to complete tests of cognitive functioning is one possible reason why some people with dementia declined to take part in the study.

There were no notable differences in awareness scores between people with dementia living with partners and those living by themselves. People with dementia who have partners might be expected to have greater awareness, because partners may voice their concerns about the memory problems of the people with dementia.

Alternatively, they may have less awareness because partners may tend to take over with tasks that need doing, giving the person with dementia less opportunity to become aware of the full extent of their difficulties. It is usually the carers of people with dementia who tend to implement memory strategies as opposed to the people with dementia themselves. Therefore, it was felt that people with dementia living with partners may have been at an advantage with regards to the implementation of any techniques discussed. However, this did not appear to be the case. Partners reported that the people with dementia did not discuss what had happened in the sessions, and even when specifically asked provided little information. The aim was

that people with dementia and their partners would discuss memory strategies that it would be useful to try at home between themselves, but this did not seem to occur. From the information that people with dementia did provide, partners gained the impression that session content varied considerably from their own. This suggests that people with dementia may have mentioned the various other topics they chose to discuss in sessions and they may have attached more importance to these than the core component of memory techniques, or felt more comfortable discussing the former issues.

Another issue was whether partners did too much for the people with dementia, which was a concern voiced by both parties in Group C. This meant that the latter may not have had the opportunity to make use of memory aids. In turn, this meant it would be harder to implement memory strategies at home because it would involve both people with dementia and partners changing their behaviours. The mean scores for the Rivermead Behavioural Memory Test were substantially higher at both pre-intervention and post-intervention for people with dementia living with themselves compared to those living with partners, but this result is artificially high due to results obtained by one participant. The only other notable differences is that the mean score for anxiety was lower at pre-intervention for people with dementia living with partners, but as mentioned this was the result of individual differences.

Qualitative findings

Moving on to qualitative findings, the idea that people can gain support from meeting others in a similar situation was borne out by comments from the partners of people with dementia but far less so for the people with dementia themselves.

Although the groups for people with dementia received positive feedback, as discussed previously this did not match with perceptions of the group and may have been because people felt they should be polite about the group. However, the people with dementia did state that it had been useful to meet with others and they said they appreciated the fact they had been given the opportunity to discuss issues they wanted to. Certainly, the most interaction in Group C seemed to occur when participants were discussing topics they had raised themselves as opposed to issues initiated by the group facilitators.

There were also a number of clinical observations made about the group. A wide range of issues was discussed in the groups. For people with dementia this included driving, retirement, how to keep memory at the same level and whether it was helpful to rely on partners all the time. Partners discussed whether they were making the people with dementia too dependent by doing too much for them, having to take on new roles, the difficulty with having to cope with the news of the diagnosis of their partners and support their families at the same time and what would happen to the people with dementia if the partners were no longer around. A wide variety of issues were also discussed in the support group described by Hawkins and Eagger (1999), in this case responses to diagnosis, emotions and practical issues being amongst some of the topics outlined. Although it was acknowledged in the context of the current study that session content needed to be similar in view of this being a research project, it was apparent there were other issues pertinent to participants that it was important for them to discuss. One participant with dementia was particularly affected by having his driving license revoked as a result of his diagnosis.

Although group content for both people with dementia and their partners was similar, sessions for the latter groups tended to run for longer (in fact, over the allocated time). This was due to the fact that partners felt at ease far more quickly, readily discussed issues and were more able to generate examples of difficulties the people with dementia were experiencing and their own feelings regarding the current situation. They more readily took advice from other participants than group facilitators, a possible reason for this being the recognition that others were in a similar situation to them. In contrast to the partners' group, the people with dementia did not seem to feel at ease with the group and found it harder to relate to the topics being discussed. In Group C, the initial session for people with dementia went well, but sessions 2 and 3 less so, which may have been because it became more 'real' for participants as time progressed. The later sessions were also more successful. Although the aim had been to be specific with advice it was difficult to do this because people with dementia did not produce their own examples, even when support for retrieval was provided. Even when facilitators provided her own or fictional examples, participants did not draw much on their own situation. Individual sessions run alongside the groups might have provided the opportunity for memory techniques to be discussed more specifically.

There are several possible explanations for the findings that the groups for people with dementia seemed to work less well than those for partners. The fact that people are experiencing cognitive deficits is likely to make participation in an intervention more difficult, although this was taken into account with extra support being provided. Also, lack of insight and motivation are symptoms associated with dementia. The use of memory techniques requires effort and motivation and it may be that in future studies only participants who are highly motivated to take new

techniques on board should be considered. Level of insight may also been an issue. In the previously mentioned study reported by Koltai et al. (2001), in which a range of strategies, including spaced retrieval, a face name recall technique and implementation of external memory aids were drawn on, a retrospective analysis showed that participants who had the most insight into their memory difficulties performed better. Unfortunately, recruitment difficulties in the current study meant it was not possible to select only participants with particularly high levels of insight and motivation, but this would be important to consider in future studies.

Another reason why people with dementia in the current intervention may not have appeared very interested in discussing memory techniques is that they may have experienced difficulties in recalling what had been covered in previous sessions. The sessions did tend to build on each other to an extent and therefore it may have been difficult to participate with only limited knowledge of the previous week's session. Attempts were made to facilitate recall by starting each week with a summary of the previous session, but it was appreciated that this did not wholly compensate for potential difficulties. Having said this, some participants did report that the sessions were slightly repetitive.

Another difficulty was that the people with dementia may also have felt self-conscious about discussing their memory difficulties in a group situation, particularly in the early sessions when they were less familiar with other participants. Discussion of memory techniques may also have evoked an emotional reaction in participants as it involved them thinking about their memory difficulties in a more specific way than general discussion. In future studies, it would be important to make the fact that the topics covered may be difficult for people with memory problems explicit. As

sessions progressed, the participants did generate more examples about coping strategies and offered each other advice. The participants initially addressed the facilitators but communicated with each other more as time progressed. Despite the fact that participants did not feel initially comfortable with conversing with the group about memory techniques, they seemed far happier to discuss general issues, even those relating to their memory difficulties. Some participants discussed their diagnosis, which highlights the importance of including only people who are aware of their diagnosis.

There were a number of exercises in the groups that were designed to make the sessions more interesting and demonstrate how memory works. Although these were carried out on a group basis and it was made clear that participants were under no obligation to join in unless they wished to, the exercises still seemed slightly confrontational in the group for people with dementia (in comparison, they worked very well for the partners).

The format of sessions was that the initial four weeks were spent discussing memory aids and strategies, the next two were geared towards peoples' feelings (how emotions affect memory and difficulties memory problems create in social situations) and the final session was a summary of previous topics. Sessions were arranged in this order especially as it was believed that people might feel more comfortable in talking about their feelings later on when they are more familiar with other participants. However, the sessions looking at feelings and social situations tended to work best of all for the people with dementia. Difficulty in remembering names was a problem all participants seemed able to relate to and they openly discussed feeling frustrated and embarrassed about this. This increased amount of

discussion may have been because people had become more used to the group. However, it may also have been related to content, as even in the initial session participants readily discussed their feelings concerning having dementia. It may also have been the result of participants feeling the session content was more relevant to them, as none of the people with dementia seemed to completely take on board any of the memory strategies discussed. Sometimes participants did say they would try using a particular memory aid at home, but this never actually happened, suggesting that the sharing of experiences and feelings was more important than learning how to use memory aids for this particular group of participants. Future studies should focus more on identifying what is important to participants and offering an intervention that suits their needs.

The original intention had been to have individual sessions to supplement group work and cover any pertinent issues in greater depth. For practical reasons, this was not possible, but it would have provided an opportunity to bring together what had been covered in the groups for people with dementia and their partners. In similar studies in the future, it would be useful to clarify the difference between recall and recognition with partners. While people with dementia may find it hard to remember session content, if partners had been taught how to use cues this may have helped the process. If content of sessions were discussed between meetings, participants with dementia would also be more likely to recall information. Partners did seem to feel that the people with dementia could not remember session content and questioned whether the group was useful for them on this basis. It was discussed with partners that sessions might be useful even if participants were unable to recall many details, but people with dementia may have been able to recall more information with help.

Partners were clearly curious about what had been covered in the group for people with dementia as this question was raised on several occasions, despite the fact that it had been explained initially that session content was similar. Similar handouts were provided for people with dementia and their partners at the end of each session, and it was hoped this would clarify the point. Partners also questioned why the sessions for themselves and the people with dementia were not run jointly, although this also had been discussed initially. The reasons for holding separate sessions were that issues were approached from different angles according to who the participants were. The group for people with dementia considered which type of memory techniques they may like to use themselves. Sessions for partners looked at how they could assist the people with dementia by helping them to implement memory strategies. Additionally, as previously mentioned, it took longer for people with dementia to feel at ease within the group. If both groups had been combined, it would have been likely that partners raised difficulties experienced by the people with dementia before the latter group felt comfortable with these issues being voiced. However, conversely, allocating people with dementia to a separate group may have appeared slightly stigmatising. Social meetings were requested by Group C and participants with dementia seemed to enjoy these meetings far more. However, this was unlikely to just be the result of all the participants being together. Session content was also probably a factor.

One contributory factor to the groups for people with dementia being less cohesive was that abilities of participants varied. Although one of the inclusion criteria was a score of 18 or above on the Mini Mental State Examination, this is quite an unsophisticated measure. The fact that participants varied in ability was also apparent from discussions in the partners' groups. If there had been a wider pool of

participants to draw from, attempts could have been made to match people, for example on the basis of scores obtained on the Rivermead Behavioural Memory Test, or perhaps other factors such as gender, previous occupations or interests.

It is interesting to note that a number of topics were raised in the social groups. Participants spent some time reminiscing about the past and also discussed issues relating to dementia. Couples were also interested in whether the others had completed questionnaires following the group and which members of staff had carried them out. The social groups took place after the main intervention and participants, in particular the people with dementia, may have been less willing to discuss these issues if they had not been familiar with other participants.

In addition to seeming to enjoy the social groups more than the actual intervention, participants with dementia also appeared to value the individual sessions during which measures were administered. These were often used as an opportunity to discuss any concerns about dementia or related issues and participants tended to talk at a more in-depth level than they had during the group. This may have been the result of the fact that people with dementia find it easier to process information on a one-to-one as opposed to group basis. In addition, these sessions were carried out at people's homes where they may have felt more at ease. The groups were run in the same clinic where people with dementia had assessments with the psychiatrists and other members of the team and had been given their diagnosis. Although this venue was recognised as not being ideal, it was the only viable option at the time. One participant did state that it worried him coming to the clinic for appointments with his psychiatrist because he saw people who he thought had more advanced stages of dementia than him when there. Finally, some participants seemed to talk in more

depth at post-intervention, which is likely to have been the result of being more familiar with the person carrying out the measures.

Factors to consider in future studies

A number of issues arose during the course of the study that might arise in future interventions of a similar nature, and are therefore important to take into account.

Carrying out research in a clinical setting

There were a number of difficulties associated with carrying out research in a clinical setting. One is that professionals did not seem to appreciate the importance of ensuring people with dementia met the inclusion criteria. As a matter of course, the Research Psychologist looked through the notes of all people who had been referred to ensure that inclusion criteria were met. In practical terms, this meant the Research Psychologist spent a substantial amount of time locating and looking at notes of people who did not meet the inclusion criteria, which has huge implications in terms of time with only one person carrying out the research, especially given that the notes were stored at various sites. For example, a number of people were referred who did not have MMSE scores of 18 or above. Diagnosis was another issue. A number of people were suggested who did not have a diagnosis and therefore could not be included. Another of the inclusion criteria was that people accepted their memory problems and were willing to discuss these in a group situation. This was not necessarily apparent from looking at the notes, but still had to be clarified with the relevant professional before contacting the person. Informed consent was another issue. Several initial interviews took place in which it appeared that the person with

dementia did not understand either what the course would involve or the research component and therefore it was not ethical to proceed. In other cases, professionals working with the people with dementia felt participants would be happy to participate in a group situation. However, when the Research Psychologist visited it was apparent this was not the case, which again had implications for time when only one person was managing the project. People with dementia and their partners may have felt they should show interest in the group if it was mentioned by a Psychiatrist or other health professional giving them treatment, although it was made clear by the Research Psychologist that the decision whether or not to participate had no effect on other services received from the Trust.

In addition, other professionals seemed to outline the study only briefly (for example, a number of participants were not aware of the research component prior to contact with the Research Psychologist and did not know what the group would involve). It would have been helpful for participants to be provided with more information at an earlier stage in order that they would be better placed to make a decision when the Research Psychologist visited. For the majority of cases, the Research Psychologist visited people in their homes to discuss the study, which took a substantial amount of time in travelling. In some cases, people clearly did not wish to participate and time could have been used more effectively if this had been clarified at an earlier point.

Issues of timing

It is important to consider the timing of offering such an intervention to people with dementia and their partners. It was felt that people would usually need a period of time to adapt to diagnosis before being offered a psychoeducational intervention.

However, conversely, once a certain amount of time has elapsed this type of intervention may no longer be beneficial. In Group C, some of the participants with dementia had been aware of their diagnosis for some time and therefore they and their partners were already familiar with many of the memory techniques that were being discussed. Despite this, partners reported that they had picked up tips from each other. Also, even if people were familiar with a number of the techniques it may still have served the purpose of clarifying they were using appropriate memory techniques.

Size of group and number of facilitators

Due to the cognitive deficits associated with dementia, it was felt the group for people with dementia should be fairly small, ideally no more than 4 or 5 people. One issue for similar interventions in the future is whether to begin with this number or start with a larger number to allow for attrition. Due to problems with recruiting, there were a small number of participants in two of the groups, which was recognised as not being ideal. Although it was made clear to participants at the beginning of the groups that it was fine if they chose not to talk, people in a smaller group may feel it is more obvious if they do not join in. However, in the present study it was difficult to recruit participants. It was felt that if too much time elapsed between the intervention being offered and being provided participants may have lost interest. In addition, such an intervention is likely to benefit people with dementia more if offered at an earlier stage and therefore it was important to carry out the group as soon as possible. Although it was also recognised that two facilitators for each group would be ideal, particularly with regards to the people with dementia, this did not happen on a number of occasions due to sickness and holidays.

Course confidentiality

The Patient Information Sheet explained that information would be shared with other health professionals. However, it was felt it would be useful to clarify exactly who would have access to information at the beginning of Group C, having learnt from running the previous two groups. It was also made clear that issues raised in the sessions of both people with dementia and their partners would not be disclosed to the other party by facilitators without participants' consent. The aim of emphasising this point was that participants should feel able to talk more freely. A problem with this approach, as mentioned previously, is that participants with dementia did not tend to discuss the sessions with their partners, meaning information from the two groups was not brought together. However, when group facilitators asked participants whether they would mind certain information being shared when people with dementia and partners were together, they had no objections.

Participant Information Sheet

This contained full details about the study, including a list of the types of questionnaires that would be administered. However, it was recognised that participants, particularly those with dementia, probably found it difficult to take this amount of information on board. In retrospect, it would have been better to draw a balance between the ethical issue of providing participants with sufficient information about the procedure and not overwhelming people with too much information.

Initial interviews

The original aim was to have two members of staff carrying out initial interviews with couples in order that one could spend time with the person with dementia and the other the partner. However, this was not possible because of staff shortages and only one person visited the couple. This created difficulties because in a number of cases the partner was keen on the idea of the course, but the person with dementia was less so. One strategy used was to leave the couple to discuss the course in their own time. However, this did not really work because partners would tend to try to persuade people with dementia to participate. In cases in which this seemed to be happening it was not ethical to proceed. Partners tended to do most of the talking in some cases and it was difficult to properly gauge the feelings of the people with dementia. If it seemed that the partner wanted to participate but the person with dementia was unsure, the group could not be offered to either of them.

Structure of the service

At the time of the research, people with dementia were not offered any standard interventions following diagnosis. In interviews in which measures were administered, some participants spent a considerable amount of time talking about the diagnosis, the effect on their lives and their fears for the future. As these were understandably major issues for participants it was felt it would not have been fair not to provide the opportunity for them to be voiced. This meant that in some cases it took more than two sessions to complete the measures (visits were intentionally kept to about an hour as it was felt that people might become tired beyond this point). However, as these issues seemed to be uppermost in some peoples' minds it may

have been that the current intervention was not appropriate for them at that time. Although some of these issues were raised in the actual group, there may not have been time to explore them in as much detail as people would have liked. Some participants may have benefited from some counselling regarding diagnosis before the intervention. The changing relationship between people with dementia and their partners was another issue that was raised by the latter. Again, although this was discussed in the group, participants might have liked the opportunity to explore these issues in more depth.

As mentioned previously, the majority of participants had probably never been approached for participation in a research study previously and might have felt because it was part of a study it would not benefit them further. It was felt that the more sessions it took to administer measures, the more it may add to any preconceptions about research participants had and detract from the potential benefits of the intervention.

Staff administering questionnaires and carrying out intervention

Ideally, administration of questionnaires and facilitation of groups would have been carried out by different people, but this was not a viable option due to insufficient staff numbers. Not only did this mean that people administering the questionnaires were aware of how participants had found the group, but it may also have been confusing for participants that the same people had both clinical and research roles. Some people spent time talking about their feelings about having dementia and the effect it had on their lives during interviews in which measures were carried out. This was particularly apparent at post-intervention. However, participants were

encouraged to discuss issues in the groups and may have been just continuing this at assessment interviews. In addition, as mentioned above, participants had probably had contact with clinicians only previously and it therefore might have been difficult for them to appreciate the difference between a clinician and researcher.

Coping strategies

One of the inclusion criteria was that people had insight into their memory difficulties and were willing to discuss these in a group situation. However, this is not as clear-cut as it may appear. People may often use a variety of coping mechanisms and therefore may use denial in some situations whereas accept they have difficulties in other areas. If people are using denial as a coping strategy a group intervention is probably not the best place to address this. Denial may not be the best long term coping strategy in some cases but this is probably more usefully addressed on an individual as opposed to group basis. Leading on from this it may be important to consider whether people grouped together should be those who have similar coping mechanisms.

Group versus individual interventions

It is not possible to tailor group interventions to individual needs as much as one-to-one interventions. In view of this and the fact that a number of potential participants did not seem to like the idea of a group situation, it was decided to offer the same intervention to couples, with the idea that each couple would be seen separately. However, due to a lack of referrals, the fact the course would not have been suitable for some potential participants and others either did not like the idea of being in a

research study or were not interested in the idea of looking at memory techniques, only two couples actually participated and neither of these completed (one completed three sessions and the other five). As previously, it was a major problem obtaining suitable referrals. It was felt the individual sessions were probably not entirely suitable for either of the couples but due to the fact that they seemed keen on the idea of them and there may have been some value from the sessions, it was decided to try them.

Implications arising for clinical practice

It is important to adapt interventions to individual need. The main considerations with regards to the person with dementia should be level of cognitive functioning, time elapsed since diagnosis and degree of adjustment to it, coping mechanisms, familiarity with memory strategies and importance attached to them and levels of insight and motivation. Whether or not the person with dementia is living with a partner and if so, the nature of the relationship between them is another issue. Not all people will benefit from a group intervention; for some individual interventions might be more appropriate. In other cases, partners may be well suited to a group intervention, while the people with dementia are not.

Implications for practitioners

It may appear that group interventions are advantageous because they allow an increased number of people to be seen at any one time. However, this is not necessarily the case. As the present study shows, a number of people, particularly those with dementia, may not like the idea of participating in a group. Therefore, as

was the case in the present study, a considerable amount of time may be spent in discussing the content of the intervention with people, but the majority of them may decide not to participate. The issue may not just be a result of the group itself, but the venue.

Summary

Although there may be a place for group interventions with people with dementia and their partners a number of factors need to be considered. People with dementia should be carefully matched in terms of cognitive ability and the present type of intervention would probably only be useful for participants who have insight, have the ability to and are comfortable with discussing their memory difficulties and are motivated to use memory techniques. In cases in which people with dementia would probably not benefit from such an intervention, it may be worthwhile offering an intervention to their partners. Also of paramount importance is considering individual differences and what types of intervention (if any) people would benefit from. The timing of this type of intervention is important: neither too soon after diagnosis or after a considerable amount of time has elapsed. The potential difficulties of working in a clinical setting, and corresponding recruitment difficulties, should be taken into account.

However participants, particularly partners of people with dementia, clearly can derive support derived from meeting others in a similar situation. Discussion of memory techniques is also beneficial. Even if participants are already familiar with some of the strategies it clarifies that they are using the right kind of approach and discussion between group members can lead to ideas for new memory techniques or

adapting existing ones to other situations. People with dementia may not benefit from discussions regarding memory techniques to the same extent, unless they have sufficient insight into their difficulties and are highly motivated to use memory aids. However, they may benefit from having the opportunity to meet with others and discuss current areas of concern.

Future studies should consider careful selection of participants on the factors outlined in this discussion and planning content of intervention on the basis of what individuals say they would like if any. In cases where the person with dementia does not wish to participate, it may be useful to offer an intervention for partners.

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Appendices

Appendix 1 –Tables of published research

Behavioural interventions

Authors, Intervention, Quality, Details	Description of Treatment Group	Outcome following treatment
<p>Teri, Logsdon, Uomoto and McCurry (1997)</p> <p>RCT, masked, 4 arms, pre assessment, post assessment and follow-up.</p> <p>Patients with dementia and their caregivers, all people with dementia met NINDS-ADRD criteria for probable AD, had had cognitive difficulties for at least 6 months, lived with their caregivers at home and had major or minor depression. There were 88 patient caregiver pairs at start of the study.</p> <p>72 completed the pretest, intervention and post test.</p>	<p>2 interventions 1) increasing positive effects and 2) problem solving techniques. There was a session every week lasting 1 hour for 9 weeks.</p> <p>Identifying pleasant events also included in second type of intervention but also included were education, support and advice.</p> <p>22 control conditions: standard care and wait list control.</p>	<p>The aim was that the interventions would reduce depression in people with dementia although not in caregivers, although this was also looked at.</p> <p>There were no significant differences in people with dementia in each of the 4 groups in cognition, behaviour or level of functioning or depression at the beginning of the study.</p> <p>There were significant improvements in depression in both intervention conditions compared to the standard care and wait list control.</p> <p>This effect was smaller in the first group (the pleasant events intervention) but there were no significant differences between the 2 intervention conditions.</p> <p>There were also no significant differences between the 2 control conditions.</p> <p>Overall, 25 people with dementia in the intervention conditions showed a significant improvement compared to only 6 in both of the other 2 arms of the study.</p> <p>If people with dementia had a diagnosis of major depression at the beginning of the study and didn't have this diagnosis at the end of the study this was judged to be a significant improvement. The same was true if people had a diagnosis of major depression.</p> <p>Only the 2 intervention</p>

		<p>conditions were followed up for ethical reasons. Positive effects were maintained. MMSE scores for people with dementia had fallen but this would be expected. People that benefited most from the intervention were those with a diagnosis of minor or major depression and people who benefited the least were those with cognitive difficulties.</p>
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Psychotherapy

Description of Treatment Group	Authors/Intervention/Quality/Details	Outcome following treatment
Cheston (1998) review of psychotherapeutic work with people with dementia.	Psychotherapy, counselling skills, cognitive and behavioural psychotherapy (e.g. Teri and Gallagher Thompson) Resolution Therapy (Goudie and Stokes, 1989) Validation Therapy (Bleathman and Morton, 1988, Feil, 1990, 1993), interventions based on operant behavioural concepts (Whitehead, 1991) Group sessions (Akerland and Norberg, 1986) Educational and emotional support (Yale, 1991, 1995).	Authors conclude that there have been many more psychosocial interventions over last 10 years but these have been evaluated using formal outcome measures in very few cases. Feedback from participants as a sole indication of effectiveness is common. However, authors also point out it is difficult to know best way to assess effectiveness of interventions when cognitive abilities of people with dementia will decline over time.

Psychoeducational Studies

1. For caregivers of people with dementia.

Authors/Intervention/ Quality/Details	Description Treatment Group	Outcome following treatment
<p>Chiverton and Caine (1989)</p> <p>Spouses of people with Alzheimer's Disease.</p> <p>40 people (47 initially)</p> <p>Alternately assigned to intervention or control group</p> <p>20 intervention group</p> <p>20 control</p>	<p>Educational programme.</p> <p>3 sessions each lasting for 2 hours.</p> <p>Presentation by group leaders & discussion.</p> <p>Topics included:</p> <p>information about dementia, managing behaviour & techniques for everyday living.</p>	<p>Coping ability significantly improved following intervention as assessed by Health Specific Family Coping Index (HSFCI)</p> <p>There were also significant improvements following the intervention in knowledge , therapeutic competence & emotional competence.</p> <p>Group leaders felt some discussions took place but for some of the participants this was too much information& they were not ready to hear it.</p>

<p>Brodaty, Roberts and Peters et al.(1994) Quasi experimental controlled intervention trial for caregivers (spouses, sons, daughters, friends) of people with moderately severe dementia. 3 groups:</p> <ol style="list-style-type: none"> 1. Those who completed training, n = 33 2. Those who partially completed training, n = 22 3. Control, n = 26 <p>Some people with dementia went into residential care during the study. In all; 4 people dementia were admitted to: 4 in group of people who had completed intervention, 2 in group who had partially completed intervention & 6 in control.</p>	<p>18 hours spread over 4 months. Adult education model including didactic information, group process, experiential learning, problem solving. Issues covered: disease process; communication and behavioural problems, physical and emotional impact on the carer, problem solving techniques.</p>	<p>Measures used: Problem Behaviour Checklist, Family Burden Interview, General Health Questionnaire, Satisfaction with Life Scale, Positive and Negative Affect Scales, Multiple choice questionnaire to assess level of knowledge. There were no significant differences between the 3 conditions on any of the measures. Caregivers with more formal education did not gain more from the intervention. The data was analysed further, this time comparing completers & controls and people who had partially completed & controls but results were not significant. There were some subjective positive findings, for example how the caregiver felt about the person with dementia. 62% of participants said they felt the intervention had been useful. Although people with dementia increased in amount of difficult behaviours & severity of dementia over time there were no significant differences between the 3 groups. Only 67% power.</p>
<p>Brodaty, Gresham and Luscombe (1997). Participants were people with dementia and person living with them, 93% of these were spouses. People mainly had Alzheimer's Disease and multi-infarct dementia. Caregiver training programme 96 participants Group 1=Immediate training group, n= 33 Group 2 =Wait list group (entered the programme</p>	<p>10 day structured memory retraining and activity residential intervention. People with dementia had separate intervention e.g. as occupational therapy, outings, group discussion & RT. Intervention for caregivers included: discussion, support groups, looking at new ways of thinking, coping skills, how to manage difficult behaviours.</p>	<p>Main outcome measures were nursing home admission and time until patient death. 64% of patients in immediate training group, 53% of wait list group and 70% of memory retraining group had died. Nursing home admission had occurred in 79% of the immediate training, 83% of the delayed and 90% of the memory retraining group. Follow up after 8 years showed that for the training group people with dementia stayed at home significantly longer & also generally lived longer (not</p>

after 6 months), n =32 Group 3 = caregivers received 10 days respite (while people with dementia had memory training programme) but no training.		significant).
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Psychoeducational studies continued.

1. For caregivers

<p>Glosser and Wexler (1985) Does not state how many participants overall. Groups offered 3 times a year to 10 - 20 participants. Relatives of patients with Alzheimer's Disease and other dementias. Half of participants were relatives of people recently given a diagnosis of dementia & others were caregivers whose relatives had mid to late stage dementia. Most caregivers were children. No control group.</p>	<p>8 week educational/support groups including information about Alzheimer's Disease, coping skills for behavioural & other difficulties & advice regarding legal & financial issues, as well as supportive function.</p>	<p>No formal measures were used. Overall rating by participants that groups were helpful.</p>
<p>Mittelman et al. (1995) RCT 206 participants (who participated for at least 1 year) 103 Treatment Group 103 Control Group RCT Spouse caregivers of people with Alzheimer's</p>	<p>Individual and family counselling, further counselling if required, support groups. 6 individual and family sessions in a 4 month period. Included role play, difficult behaviour & how to get support. 4, 8, 12 month follow ups and every 6 months after this.</p>	<p>There was a significant effect for depression in favour of the intervention after 8 months. In the first year depression scores of the intervention group were constant whereas those of the control group increased. These became significantly different at the 8 month point. At pre-intervention 40% of caregivers had depressive symptoms.</p>

Disease		
Mittelman et al. (1993) Same study as above 206 spouse caregivers RCT	As above.	After a year, half as many people with dementia had been admitted to nursing homes in the intervention group. 11 placements intervention group and 24 in control group.
Mittelman et al. (1996) Same study as above RCT 206 spouse caregivers People were followed up for up to 8 years.	As above.	The main outcome measure was time from starting study to placement of the person with dementia in a nursing home. The median time from baseline to nursing home placement was 329 days longer in the intervention group than control group (significant). Most likely to be admitted were patients with mild or moderate dementia. Important to note that counsellors encouraged spouses to place people with dementia in nursing home if appropriate. People with dementia were more likely to be admitted to nursing homes caregivers if caregivers had higher depression scores but the most important factor was caregivers' reactions to difficult behaviour. Authors stated that further counselling to address difficult behaviours may be beneficial.

<p>O'Connor et al. (1991). People were allocated according to area they lived in. 86 people in treatment group and 73 in control condition. Groups were equal social and psychiatric status at time of diagnosis; however people with mild dementia in the intervention group scored less well on the screening test & fewer received meals on wheels.</p>	<p>Wide range of help including financial benefits, physical aids, home helps, respite admissions, practical advice and psychiatric assessments.</p>	<p>Main outcome measure was whether people were admitted to residential care. 9 out of 14 participants (64%) in intervention group were admitted to residential care in study's second year compared with only one of 13 (8%) in control group. Participants with mild dementia in intervention group were more likely to be admitted to residential care than control group although this was not significant. The authors cited a possible reason as being that the intervention enabled people who the best course of action would be to being admitted to residential care being identified earlier on that they otherwise would have been.</p>
<p>Marriot et al. (2000) Single blind RCT Experimental group: family intervention Control Group 1: in depth interview (Camberwell Family Interview, CFI). Control Group 2: No interview. Blind independent assessment. 14 Ss in each group. People with Alzheimer's Disease and carer living with them.</p>	<p>Carer education, stress management and coping skills. 14 sessions. Sessions were every fortnight.</p>	<p>There was a significant change in both in distress and depression in intervention group in favour of the intervention compared with both control groups at post-treatment and follow-up. The CFI interview by itself did not lead to any significant improvements. Giving people information was not useful if that was the only input provided.</p>

<p>Ostwald et al. (1999) RCT Facilitator masked as to who receiving intervention 117 families, 72 in immediate condition and 45 in 5 month wait list condition. 94 completed the programme, 12 discontinued the intervention and 11 in the wait list control group. Participants were caregivers of people with mild to severe dementia, at home, people with dementia had behavioural difficulties and were able to come to some of the sessions with the caregiver. RCT</p>	<p>7 session workshops. Began new workshops at 2 month intervals which focused on linking dementia produced deterioration of cognitive functioning to changes in care receivers behaviours and emotions and day to day management. 7 sessions Person with dementia invited to attend concurrent group.</p>	<p>For intervention group level of burden increased significantly from pre-intervention to post-intervention and decreased significantly from post-intervention to follow-up. This was not significant until 5 months that suggests a delay in the effects of the treatment. For wait list control group there was a significant (although smaller) decrease in burden from pre-intervention to post-intervention and a significant increases from pre-intervention to post-intervention. Depression did not change significantly although did increase for both groups during the intervention and fell again afterwards if people had not obtained scores higher than the cut off point for depression. In terms of caregiver's response to difficult behaviour there was no significant changes when considering the intervention only but an effect of time was found with scores decreasing from pre-intervention to post-intervention (significant) and post-intervention to follow-up (not significant). There were no significant changes for the wait list control group. There were no significant changes in the actual difficult behaviour of people with dementia. There was no significant changes in cognitive functioning of people with dementia from pre-intervention to post-intervention but there was a significant decline from post-intervention to follow-up.</p>
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<p>Haupt, Karger and Jänner (2000) 14 patients and caregiving relatives participated in the study.</p>	<p>3 month group intervention with caregivers of people with Alzheimer's Disease. There were 2 groups with 7 caregivers in each. Group meetings were for 90 minutes and took place once a week for 12 weeks in total. Within the 12 week intervention the participants were given a wide range of information about dementia e.g. symptoms, diagnosis & progression, behavioural & psychological issues, problems caregivers may have. Intervention included psychoeducative training, psychotherapeutic strategies and specific cognitive behavioural techniques with to learn problem solving & how to implement behavioural strategies at home. modification within the care process.</p>	<p>There was significant change in agitation and anxiety in people with dementia in favour of the intervention. BEHAVE-AD was used as a measure which contains 6 subscales, delusions, hallucinations, agitation, aggressive behaviour, depressive symptoms and anxiety & there were only significant changes on these 2 scales.</p>
<p>Jänsson, Almerg, Grafstrom and Winblad (1998) Caregivers of people with dementia</p>	<p>Family caregivers and volunteers trained together in study circles. Following training volunteers spent time at home of caregivers while caregivers went out Study circles were 8 to 10 people.</p>	<p>Caregivers reported that the study circle provided the opportunity to share experiences with other in a similar situation & increased awareness that other people were having similar difficulties. Positive reports from caregivers about how volunteers looked after people with dementia & volunteers also enjoyed the experience.</p>

Psychoeducational studies continued.

2. For people with dementia and their caregivers.

<p>Moniz-Cook et al. (1998)</p> <p>Quasi experimental design (sequential block procedure)</p> <p>30 participants</p> <p>15 intervention</p> <p>15 control</p> <p>People with dementia who had recently been diagnosed & their families</p>	<p>Individualised brief home-based intervention.</p> <p>6 to 12 hours for 4 to 14 weeks.</p> <p>Included written & verbal advice on dementia, role of caregiver & crisis prevention, counselling regarding feelings of loss, looking at skills person with dementia still had & how to maintain social activities.</p> <p>Memory rehabilitation techniques with the aim of improving functioning.</p> <p>People were then referred to standard care.</p> <p>Control group has written advice only & the referred directly to standard care.</p>	<p>At 18 month follow up memory scores of people with dementia in intervention group had improved.</p> <p>Significant group x time interaction. deterioration in control</p> <p>Also significant group x time interaction on caregiver measures.</p> <p>No difference between intervention & control group in amount they used written advice.</p> <p>Well-being better for both people with dementia & caregivers in intervention group.</p>
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Reality Orientation

Authors/Intervention/ Quality/Details	Description Treatment Group	Outcome following treatment
<p>Gerber et al. (1991) RCT 24 participants, mean age = 76.5 All with probable diagnosis of Alzheimer's Disease, were in residential home & demonstrated behavioural problems. Assessed by someone masked to what group people were in. Group 1 = RO for 1 hour a day 4 times a week for 10 weeks Group 2 = Social Interaction group for 1 hour a day 4 days a week for 10 weeks Group 3 = Control, regular hospital care which did not include groups. 1 person from each of the 2 intervention groups died, 2 in Group 1 were discharged to nursing homes and 1 person from control group died before follow up.</p>	<p>Group 1 : RO for 1 hour a day, 4 days a week for 10 weeks. Activities included simple exercises, self care, food preparation and orientation in classroom like setting. Group 2 involved social activities e.g. tea parties, games, for 1 hour a day, 4 days a week for 10 weeks.. The person who made assessment of changes did not know which groups participants had been assigned to.</p>	<p>Positive effects from both interventions & these were significant, although not maintained at follow-up.</p>
<p>Baines et al. (1987) RCT 5 = RO followed by RT 5 =RT followed by RO 5 - control Participants had mild to severe dementia RO and RT cross over design</p>	<p>Group RO sessions, RO board, writing materials, old and current newspapers, photographs, materials to stimulate all senses</p>	<p>RO followed by RT group improved on measures of information/orientation and behaviour scales but this effect was lost when assessed again at 1 month. Positive feedback from staff.</p>

<p>Hanley, McGuire and Boyd (1981) Study 1 RCT 57 participants (1 dropped out) with mild to late stages of dementia from residential home. 28 participants intervention group 29 participants control group Control group received no treatment.</p>	<p>Class RO half hour sessions, 4 times weekly for 12 weeks. Used RO board, clocks, calendars, maps, posters, ward orientation training.</p>	<p>There were positive effects for intervention on Koskela (which assesses orientation, memory, concentration, association) & this was significant. Participants improved when in residential home as opposed to being in hospital.</p>
<p>Hanley, McGuire and Boyd (1981) Study 2 15 People with dementia who were in hospital. Participants were matched for gender & level of dementia. 15 participant 5 = RO 5 = RO ward training 5 = no treatment</p>	<p>Group 1: 12 weeks of 4 times weekly RO. Group 2: 12 weeks of 4 times weekly RO and 4 sessions of ward training. Group 3: No treatment.</p>	<p>No significant differences with regards to verbal abilities as a result of intervention but ward training resulted in improved orientation specifically in ward.</p>
<p>Wallis, Baldwin Higginbotham (1983) RCT n = 60 Assessors masked. People with dementia/people who were withdrawn or both. 3 RO groups 3 control groups (individual and group activities offered to them each day) If people attended less than 20 % of the time not included in analysis.</p>	<p>Intervention was half an hour for 5 days a week for 3 months. RO groups focused on orientation in time and place, names of other participants, surroundings, weather, use of everyday objects. This was done verbally & using pictures.</p>	<p>There were no significant differences between intervention & control groups in behavioural & cognitive measures. Participants with functional problems did better than participants with dementia.</p>
<p>Ishhizaki et al. (2000) 6 people with Alzheimer's Disease Mean age 79 years All late stages of dementia No control</p>	<p>Group sessions for 1 hour a day 3 days a week, classroom type setting, included RO component</p>	<p>There was no significant improvements in cognition, mental & behavioural functioning but there was no decline which the authors interpreted as positive. There was an improvement in interaction & relationships between participants developed.</p>

<p>Spector et al. (2004) Cochrane Review of studies of RO (RCTs) 6 RCTs included (8 originally identified but only 6 were entered into metaview) Breuil (1994) Woods (1979), Ferrario (1991), Gerber (1991), Wallis (1983), Baines (1987) Total 125 Ss 67 in experimental groups, 58 control groups overall Older adults aged > 55 with diagnosis of dementia. At least 60% of Ss had to complete study</p>	<p>Criteria for including studies was that there had to be at least 10 meetings for 3 weeks or more for 30 to 60 minutes. Each group had to have a minimum of 4 participants. Involved using orientation.</p>	<p>There were significant improvement in cognition & behaviour for the intervention groups but positive effects seemed to be lost at follow-up. It may be that continued intervention is needed if any effects are to be maintained. It is important to note that Breuill's study (1994) dominated the results for cognition & behavioural measures were only used in 3 studies.</p>
<p>Reeve and Ivison (1985) Intervention and Control Group, 10 participants in each. Participants had a diagnosis of dementia. After first 4 weeks of intervention (classroom RO) experimental group was divided into two groups of five. Group 1 received further intervention and Group 2 had discussion. All groups received environmental manipulation and modified informal reality orientation. Measures: Cognitive; information, orientation and mini mental status test. Behavioural Holden Communication Scale. Modified Crichton Geriatric Rating Scale. Rating scales. Ward Orientation Scale.</p>	<p>Groups 1 and 2 (initially the same group) received classroom RO 3 times a week for 4 weeks. Control group had discussion sessions for the same amount of time Intervention group then divided into two. Group 1 received classroom RO but only twice a week for 4 weeks, and then once a week for 4 weeks. Group 2 spent equivalent time in discussion.</p>	<p>No significant differences found between 2 intervention groups although Group 2 was significantly different from matched controls. Authors concluded the intervention can have positive effects in terms of cognition & behaviour which are not lost even if amount of intervention reduced. .</p>

<p>Dietch, Hewett and Jones (1989)</p> <p>3 case reports of RO.</p> <p>S1 = diagnosed with Alzheimer's Disease.</p> <p>S2 = diagnosed with chronic organic syndrome.</p> <p>S3 = diagnosed with Alzheimer's Disease.</p>	<p>S1 believed her son was 7 years old and was orientated towards the present time and place and the fact her son must be much older.</p> <p>S2 was orientated to time and place.</p> <p>S3 believed he was seeing his dead brother in the mirror and was orientated that he must be seeing himself.</p> <p>Followed by Validation Therapy.</p> <p>S1 = staff would talk about woman's son and how much she missed him.</p> <p>S2 = talking about parents.</p> <p>S3 = talking about his brother.</p>	<p>Following RO:</p> <p>S1 was upset.</p> <p>S2 had urinary frequency and incontinence for several hours afterwards (when usually continent).</p> <p>S3 became agitated and then withdrawn for several hours.</p> <p>Validation approach found to have more positive effects (no further information given).</p>
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<p>Brooke, Degun and Mather (1975) People rating participants were masked. 18 participants with diagnosis of dementia from hospital wards. 10 female; 8 male. Mean age: 73.3 years People were divided according to level of cognitive & social functioning & then randomly allocated to intervention & control groups.</p>	<p>Intervention was for 16 weeks. RO boards, keeping a diary, naming therapists & objects.</p>	<p>All groups improved in first 2 weeks but then intervention groups improved & control groups got worse. Control group was then brought into room where intervention was run & told could use any of the objects if they wanted to, but this was not taken up. There wasn't much improvement in participants in intervention group who started off with low scores; they did not do any better than control group. Some participants seemed to like sessions & people who had been withdrawn seemed to interact more. 1 participant was transferred to rehabilitation ward and eventually discharged after experiment. Overall improvement was noted to a large extent, only in 1 or 2 cases did participants become worse following the experiment.</p>
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<p>Woods (1979) 18 participants classified as elderly infirm who were in residential care. Participants had memory quotient of 70 or less on Wechler Memory Scale 3 groups Group 1 = RO Group 2 = social therapy Group 3 = no treatment 5 months later 3 participants had died & one didn't want to continue being assessed.</p>	<p>Groups of 3 to 4 participants. Half hour session led by care-staff in room using blackboard, calendar, clock, scrap-books e.t.c. Social therapy group was a discussion group & didn't used any of the above materials. Staff didn't know what expected outcome was & thought both RO & social therapy would be equally effective.</p>	<p>Participants in RO group had improved significantly more than controls at 20 weeks and also generally had done better than those in social therapy group. No significant differences between social group & controls. When scores of these 2 groups were combined they performed significantly worse than RO group at 9 & 20 weeks. No difference after 3 weeks of treatment. In terms of the concentration test, after only 3 weeks of treatment, social therapy group did significantly worse than RO and control group. RO group did better than social group at 3 weeks & this stayed the same although RO group did not seem to improve any more. In terms of behavioural difficulties these increased for all 3 weeks although did vary a lot between participants meaning some individuals may have got worse while others got better.</p>
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Support Groups

Authors Intervention Quality Details	Description of treatment group	Outcome following intervention
<p>Aronson, Levin and Lipowitz (1984)</p> <p>Community based family/patient intervention for people with dementia and their caregivers.</p>	<p>Each session was one and a half hours once a week.</p> <p>Each week started with joint session with people with dementia and caregivers. Introductions and discussion about previous week/ exercises to music.</p> <p>This was followed by separate sessions for people with dementia and caregivers. Topics discussed in the caregiver session; family, learning new activities and making changes.</p> <p>The session for people with dementia consisted of everyday activities according to the needs of the group.</p>	<p>Authors say they think the intervention met the needs of people with dementia and caregivers.</p> <p>Attendance was high & people saw each other between sessions.</p> <p>Following the intervention, participants were able to decide whether or not the people with dementia should be admitted to residential care.</p>

Support Groups continued.

<p>Hawkins and Eagger (1999) Support Group No control At time of article there were 5 members (will accept a maximum of 6). Participants had diagnosis of dementia and are aware of their diagnosis</p>	<p>Support Group covering many issues such as diagnosis, driving, research and loneliness Weekly for 1 hour over 2 years</p>	<p>Positive reports from participants. Caregivers & Day Hospital Staff felt that participants level of functioning had improved & participants started interacting outside of the group. No formal measures were used.</p>
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<p>Sainsbury, Gibson and Moniz-Cook (1996). 4 people with early dementia & 1 with functional difficulties. No control group.</p>	<p>Social Group, weekly for 8 weeks. Group decided what wanted to cover (no further information provided on content).</p>	<p>Participants stated they felt better about social situations, although this did not improve by much. No changes in affect, happiness or confidence apart from one participant who reported increased feelings of happiness. There were no changes in participants' own ratings of happiness or confidence apart from one participant who said his level of happiness increased over time. Affect scores were high for all participants & did not decrease following the group.</p>
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Support Groups continued.

<p>Thompson and Briggs (1998) Cochrane Review Support for informal carers of people with Alzheimer's Disease Participants generally over 55 years old The studies tended to consist of mainly female caregivers: only one study was half males & half females. 6 RCTs, with no significant differences between intervention & control groups at pre-intervention. Interventions were Health Care and/or Social Services. Studies were Chase Goodman (1990) (1995) Chiverton ((1989) Robinson (1994) Drummond (1991) Weinberger (1993) 8 studies were initially included but 2 had to be excluded from analysis (Flatley-Brennan, 1991 and Mohide, 1990). 7 other studies could not be included as still ongoing/need to be evaluated.</p>	<ol style="list-style-type: none"> 1. Individualised service assessment and planning 2. Technology based carer networking 3. Carer education/ training 4. Multifaced/ dimensional strategies e.g. caregiver training. <p>All the above versus standard support.</p> <p>Interventions ranged from 6 hours Chiverton (1989) to 12 months, Flatley Brennan (1985)</p>	<p>There were a variety of outcome measures meaning it was difficult to compare studies. Main outcomes were</p> <ol style="list-style-type: none"> 1. Caregiver burden/strain/ support/quality of life 2. Mental health problems 3. Use of health services/costs 4. Others such as knowledge relating to Alzheimer's Disease. <p>Conclusion is that there is no evidence for efficacy of interventions but problems with methodology etc make it difficult to draw conclusions. Positive reports from caregivers.</p>
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Support Groups continued.

<p>Zarit, Anthony and Boutselsis (1987) 184 caregivers of people with dementia. People with dementia had scores less than 20 on MMSE of less than 8 on MSQ. 40 chose not to participate after initial assessment & 25 dropped out at later point. Study lasted for 2 years & participants were selected from 2 different geographical sites. 1st site: randomly assigned to individual & family counselling or wait list. 2nd site: randomly assigned to support group or wait list control.</p>	<p>Individual/ family counselling and support groups were both for 8 sessions. During the last session of each, assessment was carried out. Last session was used to carry out post-intervention assessment. The interventions carried similar area, which were: information about dementia, behaviour problems associated with dementia, problem solving skills & ways to obtain support.</p>	<p>There were no significant changes in stress or problem behaviour in favour of the intervention. No main effects were found for income, education, relationship to patient or interactions of these variables A significant effect was found for social support over time, not for condition or condition x time. It was found that participants in the counselling intervention felt more supported than those in the control condition & this was significant. Positive reports from participants. Specific techniques such as problem solving tended to be more highly valued than general aims.</p>
<p>Mittelman et al. (1995). 206 participants (who participated for at least 1 year) 103 Treatment Group 103 Control Group Spouse caregivers of people with Alzheimer's Disease.</p>	<p>Individual and family counselling, continued counselling available after intervention & support group. 6 individual and family sessions which took place within a 4-month period. Techniques included role play, education, managing problem behaviour & obtaining support. 4, 8, 12 month follow-up and every 6 months after this.</p>	<p>There was a significant reduction in depression in the treatment group 8 months after the study had started.</p>

Support Groups continued

People with dementia and their caregivers.

Authors/Intervention/Quality /Details	Description Treatment Group	Outcome following treatment
<p>O'Connor et al. (1991)</p> <p>86 participants in intervention group & 73 in control group.</p> <p>Not randomised.</p> <p>Group were matched.</p> <p>27 out of 86 participants in intervention group died in the first year of study and 11 in second year (which was 44% of participants in total).</p> <p>In comparison 19 out of 73 participants in the control group died in the first year & 12 in the second year, making a total of 42%.</p>	<p>Wide range of help including financial benefits, physical aids, home helps, respite admissions, practical advice.</p>	<p>For people living with partners there were no significant differences in numbers admitted to institutions but with regards to people with dementia living alone significantly more in the intervention group were admitted to institutions.</p> <p>Considering each year in turn, in the first year there were no significant differences between numbers in the control & intervention group but it was the second year that made the difference.</p> <p>When both years were combined, it was found that 29 people in intervention group were admitted & 16 controls.</p> <p>There was a positive trend for people with mild dementia being more likely to be admitted but this was not significant.</p>

Emotion Focused Approaches

Authors/Intervention/Quality /Details	Description Treatment Group	Outcome following treatment
De Klerk Rubin (1998) Groups ongoing but one May - June 1998 described 6 participants all women but one died later and 2 men joined group. Participants were described as people who were confused.	Validation Group including discussion and activities that were intended to help each person's feelings of identity. Each participant had a role in the group e.g. chairperson.	Some people became more verbal or spoke more about their feelings after attending the group. It was noted that not all activities worked well.
Morton and Bleathman (1991) Pilot Study Single case design Participants = 5 (1 participant died).	Weekly validation group over 40 weeks. 10 weeks of baseline measurements, 20 weeks of validation group work (VT) and then 10 weeks of reminiscence therapy (RT).	Staff completed rating scales & these did not show any significant changes although it was noted that participants seemed to interact more following the group. With regards to participants 1 & 2 interaction increased following the VT group but reduced during the RT intervention. For participant 1 this doubled (both length & no. of statements increased) intervention during VT. For participant 2 increase in length only during VT. However, situation was the other way round for participant 4; during TR both length & no. of statements increased. Participant 3 died & there was a substantial decrease in interaction for participant 5 which authors felt was due to the death of the above.

<p>Finnema et al. (2000)</p> <p>Looked at studies involving emotion-focused interventions.</p> <p>23 studies mostly with quasi experimental or qualitative design.</p> <p>Only 4 RCTs found.</p>	<p>Validation, sensory integration, stimulation, snoezelen, stimulated presence therapy, RT</p>	<p>The conclusion was that interventions with a focus on emotions lead to positive changes.</p> <p>VT - authors stated that results are positive but methodological problems make it difficult to compare studies.</p> <p>Interventions may lead to improvements in cognitive functioning, verbal & non-verbal abilities & depression.</p> <p>Snoezelen - effect on behaviour and mood is encouraging but again there are problems with methodology & it is difficult to compare studies.</p> <p>Stimulated presence therapy – this is quite a new approach & would need to be looked at further before any conclusions can be drawn.</p> <p>RT - positive results but difficult to make generalizations.</p> <p>No firm evidence about how long positive changes last.</p>
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<p>Dietch, Hewett and Jones (1989)</p> <p>3 case reports of RO.</p> <p>Participant 1: diagnosed with Alzheimer's Disease.</p> <p>Participant 2 diagnosed with chronic organic syndrome.</p> <p>Participant 3 diagnosed with Alzheimer's Disease.</p>	<p>Participant 1 thought believed her son was 7 years old and was orientated towards the present time and place and the fact her son must be much older.</p> <p>Participant 2 was orientated to time and place.</p> <p>Participant 3 believed he was seeing his dead brother in the mirror and was orientated that he must be seeing himself.</p> <p>Followed by Validation Therapy.</p> <p>Participant 1 – the staff would discuss the woman's son & about how much she must miss him.</p> <p>Participant 2; talked about parents.</p> <p>Participant 3; talked about brother.</p>	<p>Following RO:</p> <p>Participant 1 was upset/tearful.</p> <p>Participant 2 had urinary frequency and incontinence for several hours afterwards (when usually continent).</p> <p>Participant 3 was agitated & then withdrawn.</p> <p>Validation approach found to be more effective (no further information given).</p>
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Appendix 2

Original design and intervention

When the design for the present study was planned, problems with past studies were taken into account. The original intention was to have a controlled cross-over design, with participants receiving the intervention (a group psychosocial intervention) followed by a support group (the control condition) at a later point in time, or vice versa. This design was adopted as opposed to having a no treatment condition, in order to control for therapist attention effects. Another reason was the ethical problem of withholding any form of treatment to clients in the service. A randomised controlled procedure was planned, with participants initially assigned to either the intervention or control condition. This was to take place after clients of the service had received their diagnosis and had had a period of time (of variable length according to individual difference) to adjust to this.

Both the intervention and support group condition were planned to take place for seven weeks. It was intended that individual sessions would be provided to supplement the information in the groups, meaning the entire intervention would take place over a period of three months. Measures looking at self-esteem, self-efficacy, anxiety, depression and family relationships were to be completed with both people with dementia and their partners. The perceived and actual memory functioning of people with dementia, psychiatric symptoms and problematic behaviours as perceived by the carers and their ability to cope with them were also to be assessed by the use of standardised measures. It was also considered whether quality of life

could be looked at. However, this is not an easy concept to assess and a number of measures were initially considered but decided to be unsuitable. In a revised 2

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When the design for the present study was planned, problems with past studies were taken into account. The original intention was to have a controlled cross-over design, with participants receiving the intervention (a group psychosocial intervention) followed by a support group (the control condition) at a later point in time, or vice versa. This design was adopted as opposed to having a no treatment condition, in order to control for therapist attention effects. Another reason was the ethical problem of withholding any form of treatment to clients in the service. A randomised controlled procedure was planned, with participants initially assigned to either the intervention or control condition. This was to take place after clients of the service had received their diagnosis and had had a period of time (of variable length according to individual difference) to adjust to this.

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could be looked at. However, this is not an easy concept to assess and a number of measures were initially considered but decided to be unsuitable. In a revised protocol following initial groups, a self-rating scale was used to assess quality of life. Measures were to be administered pre-intervention, post-intervention and at follow-up. A power analysis was carried out which showed that results from 30 people with dementia and 30 partners would be needed for meaningful statistical analysis. In order to obtain this number of participants, the aim was to have a rolling programme, with people being recruited for subsequent groups on an ongoing basis.

Actual study

Unfortunately, it was not possible to carry out the study detailed above. Some aspects remained as planned (e.g. the measures and the content of the group intervention). However, many of the problems arose from the difficulties associated with carrying out the study in a clinical as opposed to research setting. In addition, the Consultant Clinical Psychologist who was Head of Older Adults went on sick leave early on in the course of the research and later unfortunately died. With no Head of Service and no other Clinical Psychologists in post (and at one point no-one other than the Research Psychologist in post) fewer clients were referred to the Psychology Service. Although referrals for the study were encouraged from other disciplines, in practice a significant number came from Psychology. From the potential participants with dementia who were suggested, a number did not meet the inclusion criteria, the primary reason being that they had not received their diagnosis. The lack of potential participants meant that it was not possible to carry out a randomised controlled trial. All people with dementia who were referred and who met the criteria were asked if they would like to participate in the group in order to

obtain sufficient numbers. It did not seem realistic to try and carry out either support groups or individual sessions in view of staff shortages. The intervention therefore took place over a seven-week period (as opposed to the three month period which had been originally planned). Although the limitations of such a time-limited intervention were recognised, it was felt to be the only viable option in the circumstances.

**Appendix 3 – Correspondence to Trust’s Research and Development Group and
Local Research Ethics Committee**

North East Essex Mental Health NHS Trust

Research and Development/Audit Application`

Please return to: *Research:* *Catherine Hayes, 01206 22 8665*
 Audit: *Judith Skargon, 01206 22 8698*

Research/Audit Ref. No

Project Leader name, job title, Contact Address and Telephone Number

Julie Scott, Research Psychologist, Psychology Department, Kings Wood Centre,
Turner Road, Colchester, Essex, CO4 5JY
Tel no: 01206 228970

Other Project Team Members

Dr Peter Grahame – Director of Elderly Services
Anne Fawcett – Consultant Clinical Psychologist, Nazir Shivji – Business Manager
Linda Clare, Lecturer in Psychology, University College London

Please note: the Project Leader is responsible for, a), ensuring that any recommendations about undertaking the project are acted on, and b) forwarding a copy of the completed work (or abstract and references) to the Research Facilitator or Audit co-ordinator.

Project Title:

Effectiveness of Psychosocial Interventions in Early Dementia

Start/Finish Dates:

November 1999 – November 2002

Protocol:

In not more than 4 sides of 12 point on A4 Paper, write a protocol detailing the following headlines. (Research: this will be used for the National Research Register).

- **Principal Research/Audit question/s**
- **Methodology Description**
- **Sample Group Description**
- **Outcome Measure Description**

Questionnaires/Interview Schedules: Please enclose a copy if using these.

Please tick how you intend to disseminate your results (you may tick more than one box):


- Internal Research Forum/Team Presentation ✓
- Internal Report ✓
- Journal Publication (Please name Journal(s) International Journal of Geriatric Psychiatry.)
- Book/Chapter of a book
- Conference Paper ✓

Please tick whether you are:

- an employee undertaking research/audit as part of training []
- An employee undertaking audit []
- an employee undertaking research as part of an agreed personal development plan but not looking for external funding []
- an employee with/seeking external funding (Please also complete a research Finance Form) [✓]
- an external student using our patients []
- an external researcher []

Data Protection:

I confirm that I will keep an up-to-date back-up record of my research on disc which will be stored in a locked cupboard in another area from the computer. This will protect my data in the event of computer malfunction/theft/damage to property. This is especially important in relation to research/audit due to cross the millennium date.

Applicant's signature: 

Confidentiality:

Are you intending to consult anyone prior to accessing patient information (e.g. Service User, Key worker, Clinical lead, Nearest Relative)?

Key-worker

(Yes) / No

Local Research Ethics Committee Approval

- needed / not needed

- date obtained:

To be submitted March 2000

- LREC/MREC Ref. No.

Is this study linked with the Trust's current 'Quality Themes'?

Please describe.

The present study links in with clinical effectiveness. The intervention package is based on past research which has demonstrated the effectiveness of the techniques employed and standardised measures will be used to demonstrate change.

Research Only

Name of Research Supervisor:

Linda Clare

Is research being undertaken as part of an academic course of study:

Yes ☒ No

If yes:

Name of course:

Academic Organisation: University College London

Employees with/seeking External Funding and External Researchers:

Where do you intend to apply for/have you received external funding from:

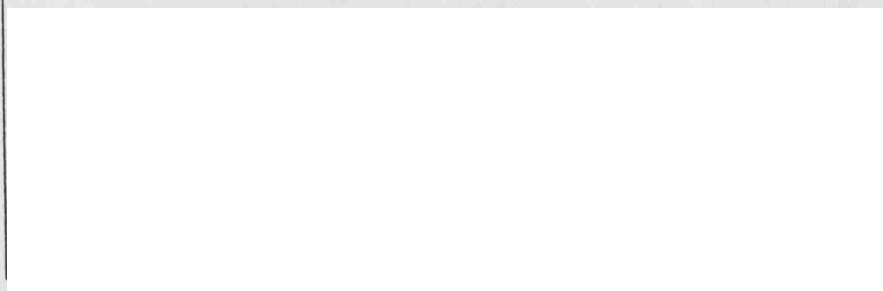
Funding for researcher post from Pfizer

What sum has been received/will be applied for: £

Clinical Negligence Declaration:

I have received and read a copy of 'NHS Indemnity Arrangements for Clinical Negligence claims in the NHS'. I confirm that I am aware of the liability my research incurs for the NHS, and I have taken all steps possible to minimise that risk. *Please note: external students and researchers must be on an honorary contract before their research begins. This will be arranged by the Research Facilitator subsequent to R&D Group approval being given.*

Signature: *J. I. Scott*

Permission of Appropriate Area Director/Service Manager/s:

The Research Facilitator and Audit team are here to help you. Please don't hesitate to ring for help if necessary and keep us informed of how the project is going. We will contact you at the end of the project, or for research allocated R&D Support money, for quarterly reports.

Memorandum

14 March 2000

to: Julie Scott

from: Catherine Hayes, Research Facilitator, 01206 22 8665

A0006 Effectiveness of psychosocial interventions in early Dementia

The R&D Group considered the above project at our meeting of 3 March 2000.
Permission to proceed with the above project is granted subject to LREC approval
being obtained.

~

The R&D Group would like to feed back the following comment:

- that this project is very well designed.

Please send me a copy of your research when you have finished.



**APPLICATION TO THE NORTH EAST ESSEX RESEARCH
ETHICS COMMITTEE**

What the LREC expects from you

For LREC applications:

Please tick the boxes to confirm these items are enclosed:

- A completed LREC application containing the appropriate Department Head signatures/
Academic Supervisor



This form should be completed in **TYPESCRIPT**. This form is now available on disk. Please send a blank 3 ½" diskette to the secretary of the above Committee, or alternatively, contact Dr Susan Smith of Essex Rivers or Mrs Catherine Hayes of NEEMHT. Please type your own details in italics to distinguish them from the Application Form and return **15** paper copies of the form (**collated please**) to:

The Chairman
Local Research Ethics Committee
C/O North Essex Health Authority Offices
Turner Road
COLCHESTER Essex
CO4 5JR

- Plus a protocol detailing:



- Principal Research question
- Methodology Description
- Sample Group Description
- Outcome Measure Description

(If you are basing your protocol on an academic essay, please remove long descriptive passages about what methods are.)

- A patient information sheet written to 'standard' level on the Flesch Formula, or
for children, the appropriate age using the Gunning's Fog Formula (ask our secretary for
details if necessary) detailing:



- what the research is about.
- how the research might benefit the patient, or that there is no advantage to them.
- they do not have to give a reason for not participating in the research.
- their care will not be affected if they choose not to participate.
- they may choose not to answer any question
- they can change their mind about participating at any point during the research.

A written patient information sheet is mandatory.

- A consent form. We have standard consent forms available for you to use. Please ask our secretary. ☒
- Any questionnaires being used. ☒
- An interview schedule if you are planning semi/un-structured interviews. ☐
- A draft of any letters to GPs, Schools etc. ☒
- Researcher's C.V. ☒

Incomplete Applications will be returned. Applications must be received at least 14 days before the next meeting of the committee (which meets every month). For dates of meetings and closing dates, please telephone between 1-5 pm (01206 288531).

For MREC applications see SOP1.

What you can expect from the LREC

- North East Essex LREC is ICH GCP compliant. Please see our Constitution for an extract of ICH GCP rules relating to LRECs.
- We may ask you to attend our meeting depending on how full our agenda is, or you may request to attend our meeting. If it is very important that your research is passed at that meeting, it is very helpful to us for you to be there.
- Our standard is to give our written decision within two weeks of the committee meeting where your research is considered. See also SOP 1.
- Where approval to proceed is subject to conditions, they will be set out clearly.
- If permission to proceed is refused, you will be given clear reasons for this decision. You may give the committee further information to support your case and request that the committee reconsiders their decision.
- Each LREC is an independent committee of the Local Health Authority. Although they have a common framework, it is not unusual for committees to interpret research differently (this is why MRECs were introduced). Independence is jealously guarded to prevent powerful researchers from forcing their point over a local view, as represented by the LREC, as to whether research is ethical or not. If you feel that the LREC is not operating to ethical standards you are free to complain to the Health Authority providing you have already requested the LREC to reconsider their decision.

GENERAL INFORMATION

1. TITLE OF PROJECT:

Effectiveness of Psychosocial Interventions in Early Dementia

2. NAME OF MAIN APPLICANT FOR THE PROJECT:
(eg: Clinical Consultant):

NAME: *Julie Scott*

QUALIFICATIONS: *B.A.*

ADDRESS: *Psychology Department
Kings Wood Centre
North East Essex Mental Health Trust
Turner Road
Colchester
Essex
CO4 5JY*

POST: *Research Psychologist*

TELEPHONE: *01206 228970*

3. NAME OF SUPERVISOR FOR THIS PROJECT IF NOT MAIN APPLICANT:
(eg Consultant for Clinical Study, Course Tutor or Research Nurse for other studies)

NAME: *Anne Fawcett*

QUALIFICATIONS: *BSc, MSc*

POST: *Consultant Clinical Psychologist*

4. NAMES OF ALL OTHER RESEARCHERS INVOLVED WITH THIS STUDY:

NAME: *Linda Clare* QUALIFICATIONS: *M.A. , MSc., C.Psychol*

POST: *Lecturer in Psychology, University College London*

NB: If patient treatment is involved, a Clinical Consultant must be named

5. GIVE BRIEF SUMMARY OF THE PROJECT, STATING ITS AIMS:

The research aims to investigate the effectiveness of psychosocial interventions with people in the early stages of dementia and their carers. The intervention is designed to target the range of needs that may be experienced by the person with dementia and his or her main carer. Relationships between the intervention and changes in symptomatology, awareness of memory deficit, depression, anxiety, self-esteem, self-efficacy and family relationships will be examined.

6. SELECTION OF SUBJECTS:

Will subjects be (delete as appropriate):

BOTH PATIENTS AND HEALTH VOLUNTEERS *i.e. both people diagnosed with Alzheimer's Disease or Vascular Dementia and their main carers (if applicable).*

State: **NUMBER OF SUBJECTS:** *26-30 in each group* **AGE RANGE:** *Clients 65+*

ARE SUBJECTS PARTICIPATING IN OTHER PROJECTS: **NO**

METHOD OF SELECTION: *Clients who attend the Memory Clinic and have been given a possible or probable diagnosis of Alzheimer's Disease or Vascular Dementia by the Consultant Psychiatrists will be identified and asked if they would like to participate in the study. If clients reside with carers, they will also be approached. Clients may be visiting the clinic for an initial assessment or currently on the caseload. The inclusion criteria is that people are in the early stages of dementia (therefore psychosocial interventions are appropriate), indicated by a score of 18 or above on the Mini Mental State Examination.*

WITHDRAWALS AND EXCLUSIONS: *It will be made clear that either client or carer can withdraw at any time during the research, and service received by North East Essex Mental Health Trust will not be affected. If there is any deterioration in the client's condition, medical advice will be sought immediately*

7. STATE START DATE AND LIKELY DURATION OF STUDY PERIOD:

March 2000 – November 2002

8. STATE LOCATION OF STUDY:

Kings Wood Centre, Colchester

9. EFFECTS ON OTHER DEPARTMENTS:

Does the study incur work on the following local departments?

X-ray	NO	
Pathology	NO	
Pharmacy	NO	
Other Departments	NO	WHICH? N/A

If YES, how are these to be funded? *N/A*

If work is incurred to the local department, the signature of the Departmental Head is requested below to indicate that satisfactory arrangements have been made between the Researcher and Head of Department.

DEPARTMENT (list)

SIGNATURE OF DEPARTMENT HEADS

10. CONFIDENTIALITY

How will subjects confidentiality be safeguarded?

All clients will be identified by code number only. Master list will be kept under lock and key at King's Wood Centre, Colchester.

To whom, if anyone, will disclosures be made?

To clinicians within the elderly CMHT and Consultants, should it be clinically necessary.

How and where will files/data be stored?

All files and discs will be kept at the King's Wood Centre under lock and key.

If data is to be stored on a computer, is this registered under the Data Protection Act?

Yes

How and when will records be destroyed?

Upon completion of the project.

11. SUBJECT INFORMATION AND CONSENT

How will subjects be informed about the nature of the study?

VERBALLY / INFORMATION SHEET

Both – information sheet provided.

(provide example Information Sheet with each Protocol or enter sample of exact wording to be used below).

Informed consent should normally be both **WRITTEN** and **WITNESSED**.

Please confirm that the consent will be **WRITTEN:** **YES**

WITNESSED: **YES**

If **NO**, explain why written consent is not being obtained:

If **NO**, how will the giving of consent be recorded?

12. NOTIFICATION OF GP

If patients are involved, will their GPs be informed? YES

If YES, specify methods (e.g. enclose sample letter).

Letters will be sent to G.P.s informing of clients' involvement in the study and standard letters sent as part of standard feedback from the memory clinic.

If scores on measures administered to carers fall outside normal limits and give cause for concern, permission will be sought from that person to contact his or her G.P.

If NO, WHY NOT? N/A

DOES THE STUDY INVOLVE PATIENT TREATMENT? NO

Not medical treatment

DOES THE STUDY INVOLVE INVASIVE PROCEDURES? NO

If you have answered YES to either of the above, complete Appendix I.

DOES THE STUDY COMPRISE A QUESTIONNAIRE/INTERVIEW SCHEDULE? YES

If YES, answer Appendix II.

13. FINANCIAL ARRANGEMENTS

If study initiated/sponsored by a Pharmaceutical Company or other private company, please specify any financial or other direct interest to you or to your department arising from this study.

Funded by Pfizer for 3 year period

Are any payments made to subjects? NO

Transport will be provided if necessary

If YES, specify: N/A

If study is not sponsored, how are the costs to be met?

N/A

DATE OF SUBMISSION: 15.03.00

SIGNATURE OF MAIN APPLICANT

SIGNATURE OF SUPERVISOR:

(Consultant, Course Tutor, Research Nurse) 210

APPENDIX II

QUESTIONNAIRE/INTERVIEW SCHEULE

Is the study part of a course project? NO

Not at present. Intending to make application for MPhil at future date.

If YES, has the Questionnaire/Interview Schedule been approved by your tutor? N/A YES / NO

Is the study a Patient Satisfaction Survey? NO

Has statistical advice been obtained to ensure the usefulness of data collected? YES

If YES, who from? *Dr. P Fearon, Sub-dept of Clinical Health Psychology, University College London*.....

NB:

15 sample Questionnaire/Interview Schedules must be provided.

Effectiveness of Psychosocial Interventions in Early Dementia

Background Rationale

Dementia has been defined as 'a global deterioration in mental functioning in an otherwise alert patient.' (Lishman, 1987). The most prevalent form of dementia in older adults is Alzheimer's Disease, which accounts for approximately 50% of all known cases (Cummings and Benson, 1983; Katzman, 1986). Multi-infarct dementia accounts for 18% of cases, and a further 10% are a combination of this dementia type and Alzheimer's Disease (Terry and Katzman, 1983; Tomlinson et al, 1970). These are the types of dementia being considered in the present study. Reisberg et al (1982) describe dementia as seven stages of global deterioration, resulting in dependence on others and loss of psychomotor skills. The diagnosis of dementia requires deficits in at least two areas of cognitive functioning, which includes memory, reasoning, language and spatial ability. Deterioration in memory is often one of the first recognised symptoms of dementia. In early stage dementia, it is long term episodic memory that is typically most affected, while other aspects of memory may remain relatively intact. Miller and Morris (1993) state that there will be varying effects on cognition, behaviour and personality.

In addition to cognitive deficits, there are many important factors to take into account when considering the person with dementia. One third of people suffering from dementia will show depression at some point, and this is particularly common following the initial diagnosis. Certain types of this condition are associated with damage to nerve structure and depression may, in any case, lead to an impairment in cognitive functioning. Speedie, Rabins, Pearlson and Moberg's (1990) study of the general elderly population found that some people with depression demonstrated cognitive deficits. Also, people who have been diagnosed with dementia may be treated differently and experience a decline in social interactions. Kitwood (1997) discussed how, in addition to adjusting to neurological impairment, people are required to become accommodated to the social consequences of their diagnosis, and stressed the importance of recognising the personhood of those with dementia. Additionally, the necessity of attending to carer burden has been recognised. Typically in early stage dementia, the responsibility of care falls onto the family who are themselves adjusting to the losses the diagnosis brings (Morris et al, 1988; Coen, 1998).

There is increasing recognition that that early intervention may be beneficial. Memory clinics have been established in the U.K. for specialist assessment and diagnosis of people with early dementia (Bucks et al, 1998; Fraser, 1992; Moniz-Cook and Woods, 1997). The aims of employing psychosocial interventions in early dementia include reducing distress and disability, preventing disease progression and improving quality of life for clients and carers. Psychosocial interventions can play an important role with the person with dementia, according to a meta-analysis by Knight et al (1993a), who made the suggestion that interventions should be directed at both the client and carer and tailored for individual need. A wide range of interventions for people with dementia have been discussed in the literature, including behavioural strategies, reality orientation, reminiscence, psychotherapy and validation, resolution and cognitive-behaviour therapy. Techniques used with dementia sufferers and caregivers include education, support groups and family therapy. All of these might form part of a comprehensive approach to psychosocial intervention, but evidence for their effectiveness needs to be considered.

Reality orientation (RO) was initially described by Taulbee and Folsom (1966), and can be of a 24-hour nature or classroom style, in which people regularly engage in orientation-type activities. Reminiscence originates from Butler's work on life review (1963), uses past memories to establish common interest and may be carried out in individual or group settings. Reminiscence has often been used interchangeably with life review, but the latter is a far more structured overview of a person's life. Spector, Orrell, Davies and Woods's Cochrane review (1998) of randomised studies of classroom RO with people suffering from dementia, found some evidence to support positive effects on behaviour and cognition, although not with regards to maintenance of results. The same authors carried out a Cochrane review of reminiscence therapy (1988), but found systematic research in the area to be inadequate. Only two randomised controlled trials met the inclusion criteria of the review, and it was concluded that there is not ample research evidence to form definite conclusions. Cognitive-behavioural techniques have been shown to be effective with people suffering from mild impairment, for example in a study by Teri and Gallagher Thompson (1991). Brodaty and Gresham (1989) and Mittelman et al (1996) both found significantly positive effects on carers of people with Alzheimer's Disease following multifaceted programmes.

Principle Research Questions

There is evidence to support the effectiveness of cognitive rehabilitation and psychosocial interventions. However, the results are not consistent. Interventions have tended to result in a positive change in some studies, and no change in others, although none have demonstrated a detrimental effect. Some controlled evaluation studies have demonstrated a delay in institutionalisation, (Brodaty et al, 1997; Mittelman et al, 1996; Vernooij-Dassen et al, 1995) while others have not yielded significant results (O'Connor et al, 1991). The nature of the effects has also varied between studies. In addition, Knight et al (1993b) and Woods (1995) stated that interventions have frequently been inadequately described, have failed to address the needs of the caregiver and follow-up assessments have been lacking. Interventions have also tended to target one person or area. Clare (1999) argues that these interventions need to be designed in such a way as to take account of the full range of needs implicated in the experience of early stage dementia. Brodaty et al (1994) also recommended that, in addition to addressing the needs of the carer and client, and individualising packages, a wide range of techniques are employed. From a review of the literature, key areas to consider with clients and carers have been identified, these being as follows:

- the impact of diagnosis
- the need for knowledge regarding dementia and interventions
- cognitive deficits
- depression and anxiety
- self-esteem and self-efficacy
- reactions of others
- stress and burden of caregivers and effect on family relations
- how to respond to memory and behavioural problems.

In line with suggestions by Clare (1999) and Brodaty (1994), the intervention package in the present study has been designed to target the full range of needs that may be experienced by people suffering from dementia and their carers. It will incorporate a range of components, the core feature being a mood and memory group for clients and carers. Questionnaires have been selected to measure changes in key areas indicated

in the literature. Taking into account criticisms cited above (e.g. Knight et al, 1993b; Woods, 1995) the present intervention will target the caregiver in addition to the client and incorporate adequate follow-up assessments.

As previously stated, although past research has indicated that psychosocial interventions can produce positive effects, there are a clear lack of studies which target the full range of possible needs of people suffering from dementia. The literature indicates aspects which should be included in psychosocial interventions in early dementia, and the aim of the present study is to investigate the effectiveness of a package which incorporates techniques that have been shown to produce positive results and address a wide range of issues.

Methodology Description

Please see attached form for an overview of the format of the project, which takes the form of a randomised controlled trial and cross-over design. Following initial assessment, clients routinely return to the memory clinic for a further appointment after one to three months, at which time reassessment takes place, previous results are discussed and a diagnosis given if applicable. If clients have been given a diagnosis of Alzheimer's Disease, Donepezil or Exelon may be prescribed by the Consultant Psychiatrist. Only clients with a diagnosis of either Alzheimer's Disease or Vascular Dementia, who obtain a score of 18 or over on the Mini Mental State Examination (indicating mild or minimal dementia), will be considered in the present study. Baseline measures will be administered to clients and carers on both the above occasions and scores from any standardised neuropsychological assessments recorded. Further measures will be administered at three months from this point, and randomisation will take place. Participants will be divided into three categories: i) currently taking Donepezil ii) initially prescribed Donepezil but discontinued due to failure to respond to or tolerate the drug and iii) never prescribed Donepezil. The participants will then be randomly assigned into one of two conditions, the control group or intervention group. Each of the categories will be represented across both conditions.

The control group will receive treatment as usual, and will additionally be offered the opportunity to attend a support group, in order to control for non-specific therapist effects. The intervention group will be offered a specifically designed package in addition to treatment as usual. A core feature of the package will be groups run in parallel for clients and carers, which will address a variety of issues including memory problems, relationship of mood and memory, education and coping strategies. In addition, a further group will be offered to people who live alone, which will address identical primary issues. Groups will be closed and run for seven week blocks. Each session will last approximately an hour and a half. Further components of the overall package will include individual advice and intervention relating to the memory problem, marital work aimed at enhancing understanding and communication, exploration of possible valuable roles for the client, education regarding dementia and information concerning local resources. The phase of treatment as usual or psychosocial interventions will take place for a period of three to six months, after which all parties will be reassessed. There will also be follow up assessments three and six months from this time. If possible, groups will be reversed at this point, with the control group receiving the intervention package and vice versa. The same measures will be administered at identical times. Statistical analysis will be carried out using ANOVA and, in addition, qualitative data obtained from clients and carers will be considered

Sample Group Description

Participants will be recruited from clients who currently attend the memory clinic at North East Essex Mental Health Trust, have received a consultant diagnosis of Alzheimer's Disease according to NINCDS criteria (McKhann et al, 1984) or Vascular Dementia, and score 18 or over on the Mini Mental State Examination (i.e. mild or minimal dementia). An initial pilot study is planned which is designed to investigate:

- the stringency of inclusion and exclusion criteria of participants, and whether this will result in an adequate sample size for statistical analysis
- if any modifications in the intervention package are required
- proposed measures

The core feature of the pilot study will be the mood and memory group, based on a standard protocol which will also be followed in the main study.

Clients who are new referrals to the memory clinic and identified as potential participants will be asked during initial assessment whether they would like to take part in the pilot study or main project. People currently on the caseload who meet the proposed criteria will also be asked if they would like to participate. The full purpose of the study and what it will involve will be explained to clients and the main carer and an information sheet provided. In the case of clients who do not live with a carer, the closest member of the family will be contacted if appropriate, subject to the client's agreement. The fact that there will be two groups in the study (control and intervention) and people will be randomly assigned to one of these will be fully explained. Additionally, it will be made clear that people will be provided the opportunity to participate in the alternative condition at a later point in time. At each point measures are repeated, any clarification of the study will be provided and willingness to participate will be confirmed.

Outcome Measure Descriptions

The following measures will be administered to both clients and carers

- Hospital Anxiety and Depression Scale (Snaith and Zigmond, 1994) a 14 item scale.
- Rosenberg Self Esteem Inventory (Rosenberg, 1965), a 10 item scale.
- Generalised Self-Efficacy Scale (Schwarzer and Jerusalem, 1993), a 10 item scale.
- Memory Awareness Rating Scale (Clare, 2000), a 10 item scale.
- Family APGAR, (Smilkstein, 1978), a 5 item scale.

The Behavioural Pathology in Alzheimer's Disease - BEHAVE-AD (Reisberg, 1986) will be used with the client. The clinician rates the degree of occurrence of the following: paranoid and delusional ideation, hallucinations, activity disturbances, aggressiveness, diurnal rhythm disturbances and affective disturbance, anxieties and phobias and there is also a global rating scale.

In addition, the Revised Memory and Behaviour Problem Checklist will be administered to carers (Teri, Truax, Logsdon, Uomoto, Zarit and Vitaliano, 1992), a 24 item scale.

Two group t-test of equal means (equal n's)

RBMT profile score

A sample size of 22 in each group will have 80% power to detect a difference in means of 6.070 (the difference between a Group 1 mean, μ_1 , of 12.600 and a Group 2 mean, μ_2 , of 6.530) assuming that the common standard deviation is 7.000 using a two group t-test with a 0.050 two-sided significance level.

BDI

A sample size of 66 in each group will have 80% power to detect a difference in means of -2.800 (the difference between a Group 1 mean, μ_1 , of 7.900 and a Group 2 mean, μ_2 , of 10.700) assuming that the common standard deviation is 5.685 using a two group t-test with a 0.050 two-sided significance level.

GHQ

A sample size of 7 in each group will have 80% power to detect a difference in means of -7.300 (the difference between a Group 1 mean, μ_1 , of 4.600 and a Group 2 mean, μ_2 , of 11.900) assuming that the common standard deviation is 4.255 using a two group t-test with a 0.050 two-sided significance level.

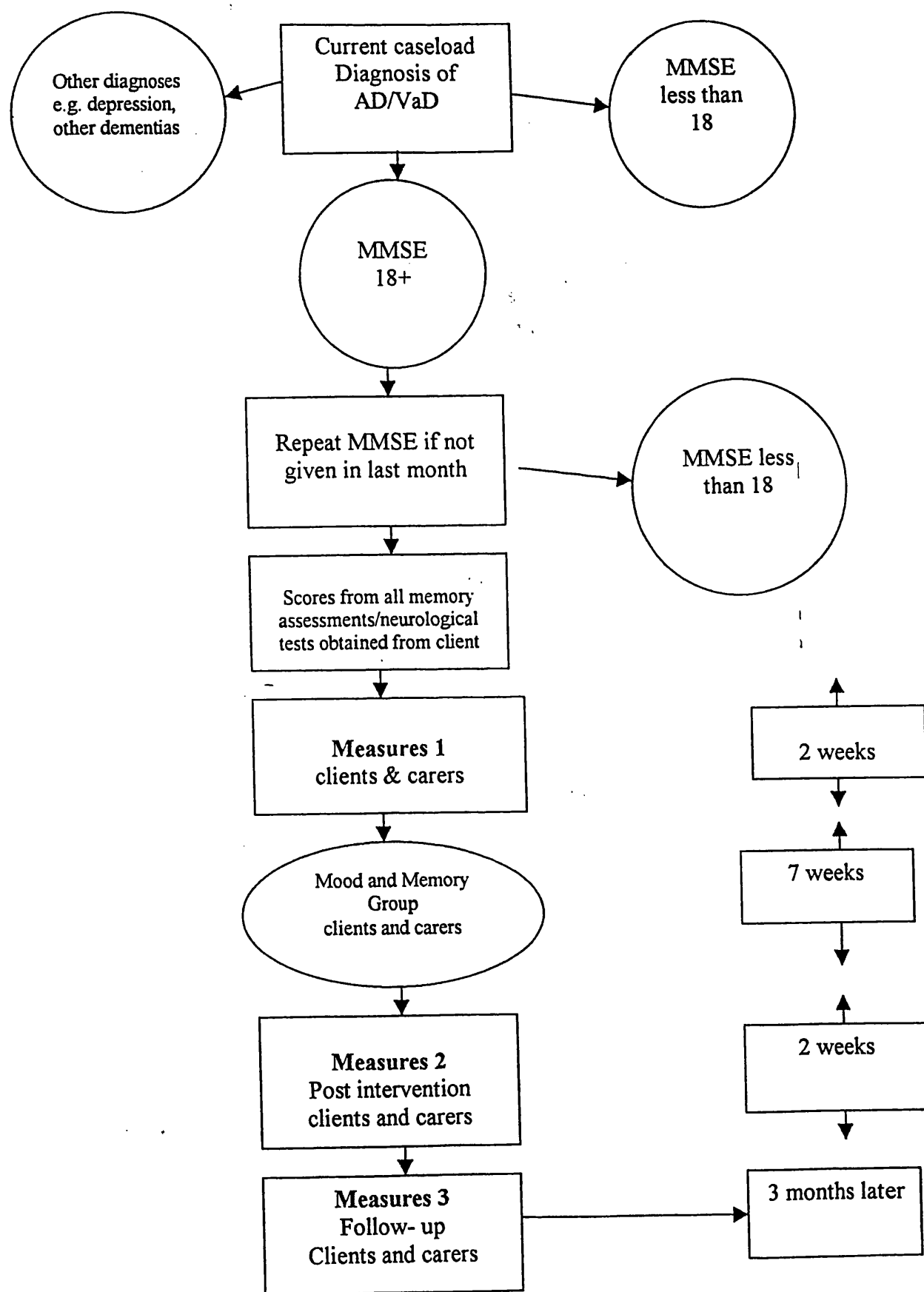
HAD - Anxiety

A sample size of 5 in each group will have 80% power to detect a difference in means of -6.840 (the difference between a Group 1 mean, μ_1 , of 5.800 and a Group 2 mean, μ_2 , of 12.640) assuming that the common standard deviation is 2.915 using a two group t-test with a 0.050 two-sided significance level.

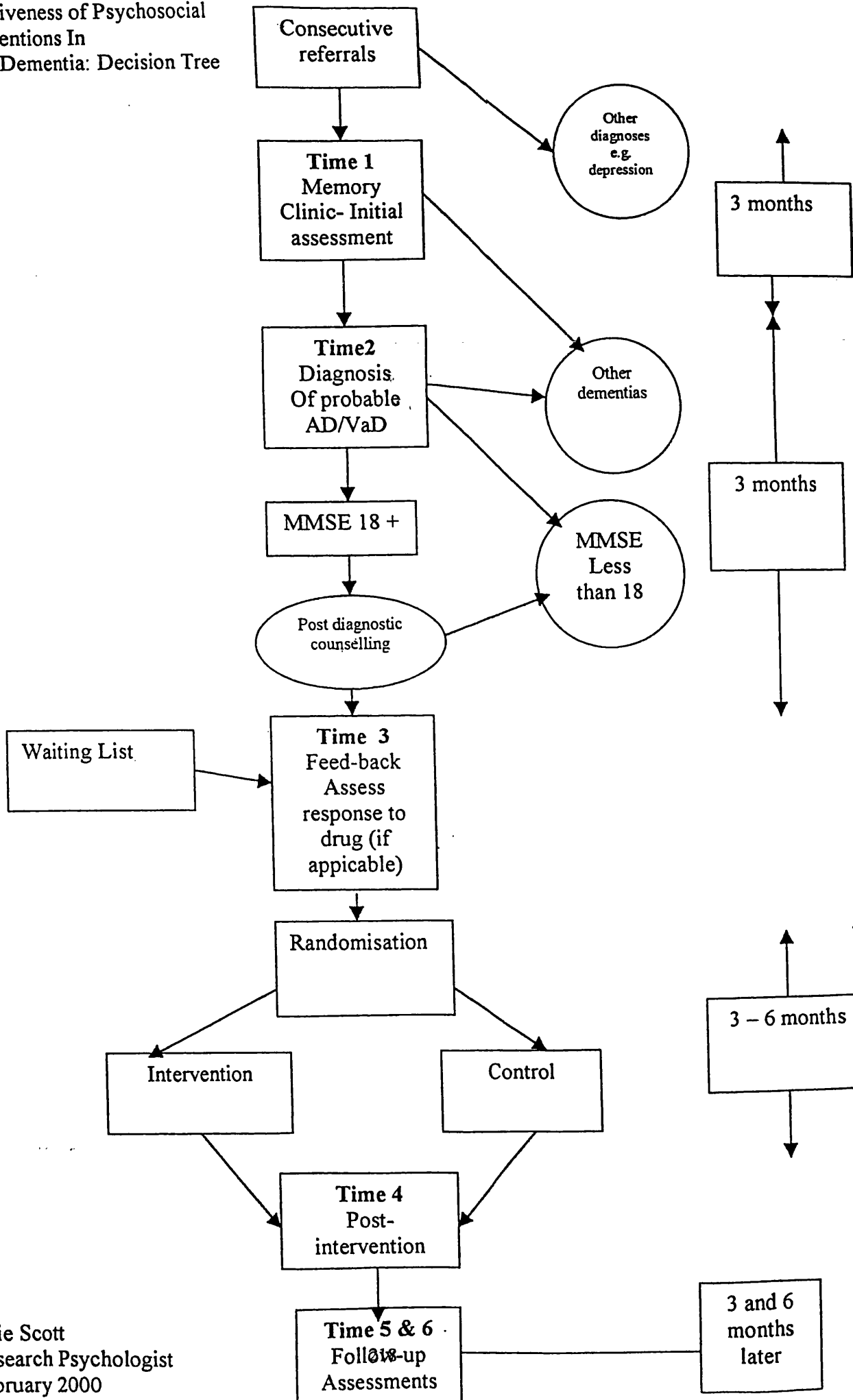
HAD - Depression

A sample size of 26 in each group will have 80% power to detect a difference in means of -2.900 (the difference between a Group 1 mean, μ_1 , of 8.400 and a Group 2 mean, μ_2 , of 11.300) assuming that the common standard deviation is 3.625 using a two group t-test with a 0.050 two-sided significance level.

Pilot Study – Effectiveness of Psychosocial Interventions in Early Dementia.



Effectiveness of Psychosocial Interventions In Early Dementia: Decision Tree



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OUR REF: MH169

3rd April 2000

Julie Scott
Psychology Department
Kings Wood Centre
North East Essex Mental Health Trust
Turner Road
Colchester CO4 5JY

Dear Ms Scott

Our ref: MH169 – Effectiveness of Psychosocial Interventions in Early Dementia

The North East Essex LREC has considered the above application at its Committee meeting on 30th March 2000. Thank you for attending. Please quote our above reference number on any future correspondence.

The LREC has no objection to this study proceeding subject to the following conditions of approval:

- The patient/participant consent forms need to include the signature of a witness. (The staff consent form was included in error).
- Please confirm records will be shredded upon completion of the project.
- Please amend the paragraph breaks at the beginning of the Information Sheet. Perhaps the first four paragraphs could become two? We suggest the first paragraph runs to '...with your memory problems' and you begin a new paragraph 'We have been running ...'.
- Could you please amend the sentence in the last paragraph of the Information Sheet page 2, to read 'You may decide to come out of the study at any time without giving a reason'.

Approval to proceed will be given on receipt of the above amendments and we look forward to hearing from you in the near future.

If we do not receive a reply to this letter within 3 months it will be necessary for you to re-present 15 copies of the research papers, including Application Form and all other supporting documents.

Chair
North East Essex Local Research Ethics Committee

North East Essex
Mental Health NHS Trust
King's Wood Centre Turner Road
Colchester Essex CO4 5JY
Telephone: 01206²²⁸⁹⁷⁰ Fax: 01206 228901

Psychology Department JS/RA

Your Ref MH169

WRITTEN: 05 April 2000
TYPED: 05 April 2000

Mr Martin Harrison
North East Essex Local Research Ethics Committee
North East Essex Health Authority
Turner Road
COLCHESTER
Essex
CO4 5JR

Dear Mr Harrison

Re: MH169 Effectiveness of Psychosocial Interventions in Early Dementia.

Many thanks for your letter, dated 3 April 2000, stating that North East Essex LREC has no objections to the above research study proceeding subject to the listed alterations.

Please find enclosed the amended patient/participant consent forms, and patient information sheet duly amended.

I also confirm that records will be shredded upon completion of the project, unless they are part of patient's medical or clinical notes.

Yours sincerely

Julie Scott
Research Psychologist

Encs



Turner Road, COLCHESTER Essex CO4 5JR
Tel No: 01206 288531 Fax No: 01206 288599

OUR REF: MH169

11th April 2000

Julie Scott
Psychology Department
Kings Wood Centre
North East Essex Mental Health Trust
Turner Road
Colchester CO4 5JY

Dear Ms Scott

Our ref: MH169 – Effectiveness of Psychosocial Interventions in Early Dementia

Thank you for your letters dated 5th and 6th April 2000 and enclosures.

All the necessary amendments as set out in our letter dated 3rd April 2000 have now been made, and approval to proceed on the above research is now given.

You will no doubt realise that whilst the LREC has given approval for your project on ethical grounds, it is still necessary for you to obtain approval, *if you have not already done so*, from the Trust in which the work will be carried out. Please contact Mrs Catherine Hayes, Research Facilitator, Trust HQ, North East Essex Mental Health Trust.

Please advise the Committee of the research progress annually and when this research has been completed.

Yours sincerely

MARTIN HARRISON
Chair
North East Essex Local Research Ethics Committee

Copy to: Catherine Hayes

2 February 2001

Mr Martin Harrison
North East Essex Local Research
Ethics Committee
North East Essex Health Authority
Turner Road
Colchester
Essex
CO4 5JR

Dear Mr Harrison

Re: Psychosocial Interventions in Early Dementia Research

Following the pilot study, there are a number of minor amendments that I would like to make to the original proposal, submitted on 15th March 2000. As you may be aware, Anne Fawcett, Consultant Clinical Psychologist, North East Essex Mental Health Trust, is currently on long term sick leave. Due to the impact on the Psychology Service resulting from Anne's absence, it will not be possible to have random allocation to conditions at the current time. Instead, all participants will be allocated to the intervention condition i.e. the Memory Courses. In addition, it will not be possible to incorporate the individual sessions outlined in the original proposal.

Below are the proposed amendments:

Inclusion criteria

- The age range of potential participants was stated as sixty-five years and above. Although participants are likely to be in this bracket, we would like to alter this to forty-five years and above to allow younger people with dementia and their spouses to participate.

- The inclusion criteria were stated in the original proposal. These have been expanded (please see enclosed sheet). It was felt that the group of participants need to be relatively homogenous in order for the group to be cohesive and relevant for all involved. The criteria have also been altered in order that they are also applicable to the service at Clacton.

Patient Information Sheet

This has been amended (please find copy enclosed), the main changes as follows:

- There are two Patient Information Sheets enclosed, one to reflect the current situation outlined above (i.e. Memory Courses offered only) and the other for use in the future when the expectation is that random allocation will be possible.



- Measures administered in the study have clinical significance and therefore copies of measures completed by clients or by spouses with respect to clients will be kept in clinical notes with the code numbers removed.
- Scores from relevant measures in patients' clinical notes will be utilised.
- The intervention condition will be referred to as courses as opposed to groups.
- The word 'partner' in the patient information sheet has been amended to 'spouse', as this appears more age-appropriate.
- The order of topics covered in Course A has been altered to follow a more logical sequence, and point three, relaxation, omitted because the other three points summarise the main components of the course (and omitted from what the course for spouses will cover).
- During pre, post and follow-up sessions when the measures are administered, an additional factor will be exploring participants' individual targets and determining whether these were met by the intervention, as reflected on the Patient Information Sheet. Please also see enclosed schedule of questions.
- Other services that participants are receiving will be recorded, e.g. Health Services, Social Services and Voluntary Organisations. This information will be extracted from the casenotes.
- The fact that medication status will be recorded has been clarified.
- The fact there will be measures and a clinician rating scale for clients and measures for spouses has been clarified.
- The point that the research will be written up and published has also been clarified.

G.P. letters

- The G.P. letters have been amended and an additional version constructed to reflect the current situation (i.e. Memory Courses offered only).

Information regarding measures

- The Rivermead Behavioural Memory Test (RMBT), Mini Mental State Examination (standardised), Hospital Anxiety and Depression Scale (HADS), and Revised Memory and Behavioural Problem Checklist (RMBPC) are standard measures used in the Memory Clinic. We are planning to utilise scores from these (the RMBPC and HADS were detailed in the original proposal). The expectation is that patients' standard appointments with the service will coincide sufficiently with the particular points in the study scores need to be obtained. If there are cases where the above measures have not been carried out, they will be administered if appropriate.
- The proposal stated that two parts of the Memory Awareness Rating Scale (MARS) will be utilised in the study, these being a 10-point scale to be completed by clients

and a 10-point scale to be completed by spouses. A third part of the test, a 13-point scale completed by clients, Memory Performance Scale (MARS-MPS) which is used in conjunction with the RBMT, is being used as a standard measure in the Memory Clinic. Scores will be utilised from this measure for the study. As above, if there are cases where the MARS has not been carried out, this will be administered if appropriate.

- Following the pilot study, it has been decided not to utilise the Family APGAR, but instead to ask the questions:

Do you feel able to talk to your family about your memory problems? (to clients)

Do you feel able to talk to your family about your spouse's memory problems? (to spouses).

Answers will be on a 5 point rating scale.

- It was decided it would be useful to use an index of life satisfaction by asking the question, 'How happy are you with your life as it is now?' to all participants.

Answers will be on a 5 point rating scale.

For information/clarification:

The flow chart in the submitted proposal refers to the standard procedure following referral to the Memory Clinic. The route may vary for individual clients.

- The expectation is that the BEHAVE-AD (mentioned in the original proposal) will become a standard measure used in the Memory Clinic. If this is the case, scores will be used from standard appointments that fall nearest to pre and post intervention, and follow-up. In the meantime, the measure will be administered as part of the study as outlined in the original proposal.

- It was stated in the original proposal participants medication status will be recorded - currently taking Donzepil, initially prescribed Donzepil but discontinued due to failure to respond to or tolerate the drug, or never prescribed Donezepil. It will also be recorded whether people have been prescribed, discontinued or never prescribed Rivastigmine. Any other significant prescribed medication will also be noted.

- It has been decided it would be useful to have standard information for potential participants displayed at the Memory Clinic and handed out for people to look at. This is enclosed for your perusal.

- There may be cases when the spouse wishes to attend the group, but the patient does not. In such cases, it will be possible for only the spouse to attend a group, provided the patient is happy with this.

- The original proposal stated that there would be follow-up sessions 3 and 6 months later. This has subsequently been revised to the 3 month point only.

- General Recording Forms will be completed after each session which consider which three topics were covered in most detail, which three in least detail and provide a general overview of the session. Entries will also be made in casenotes.

- In the original proposal, it stated that an ANOVA would be carried out for the purposes of statistical analysis. It may be that a t-test or another statistical test may be more appropriate.

- At the time the proposal was submitted, it was stated that although the study was not part of a course project, the intention was to make an application for an MPhil at a future date. The application has subsequently been made and accepted to carry out the course at University College London.

Please find enclosed;

- Inclusion and exclusion criteria
- Memory Clinic Courses (introductory sheet for participants).
- RMBT
- Memory Performance Scale (MARS- MPS)
- Family Relationships and Life Satisfaction Questions (for use by clinicians).
- Response sheets for patients and spouses for above questions
- Patient and Spouse Information Sheets (2 versions)
- GP letters (3 versions)
- Schedule of Questions for pre, post and follow-up sessions (for use by clinicians).

Many thanks for your attention in this matter. I look forward to hearing from you.

Yours sincerely

Julie Scott
Research Psychologist

Our ref:
Monday, 05 February 2001

Local Research Ethics Committee
Health Offices
Turner Road
Colchester CO4 5JR

Ms Julie Scott
Research Psychologist
King's Wood Centre
Turner Road
Colchester CO4 5JY

Dear Ms Scott

RE MH169 Effectiveness of Psychosocial Interventions in Early Dementia

Thank you for your letter of 2nd February 2001 requesting approval for amendments to the proposal approved in April 2000. There are a number of issues that must be addressed before giving approval, under chairman's action, for this amended study to continue.

Please could you supply details of both:

1. Your practice supervisor (in the absence of Anne Fawcett) and
2. Your course, academic institution and academic supervisor.

Also please evidence that the amended protocol has been seen and approved by the above persons.

• **Patient and Spouse Information Sheet**

This should now include details that your research is part of your academic study leading to a Master in Philosophy (MPhil) degree.

In addition we now require all researchers to include their name and contact details on all information sheets. I would be grateful if you would update your sheet to include your name, position, department, and contact details.

You state that you have changed your sheet to be more age specific (from *partner* to *spouse*). It would seem more appropriate to be inclusive rather than exclusive (particularly as you wish to reduce the recruitment age to 45 years). The term *spouse* excludes all those people who are not married. Please revert to the previous or adopt the term spouse/partner throughout your information sheets/consent forms.

Upon receipt of this information and satisfactory amendments being made, approval can be granted under Chairman's Action.

Yours sincerely

Martin Harrison
Chair
North East Essex Local Research Ethics Committee

North East Essex
Mental Health NHS Trust
King's Wood Centre Turner Road
Colchester Essex CO4 5JY
Telephone: 01206 228970 Fax: 01206 228901

28 February 2001

Mr Martin Harrison
Chairperson
North East Essex Local Research
Ethics Committee
Health Office
Turner Road
Colchester
CO4 5JR

Dear Mr Harrison

Re: MH 169 Psychosocial Interventions in Early Dementia

Many thanks for your prompt reply to my revised proposal, dated 5th February. Please find the amended Patient and Partner Information Sheet, in which I have replaced the term 'spouse' with 'partner,' and included the information that the project will be written up as an MPhil thesis. In addition, I have added a further point (number 8) in the summary of the information that will be included in the write-up, namely the diagnosis that people have been given. I have also slightly altered point 9 below this (previously point 8) and point 3 under 'Your Patient Notes,' to improve the readability.

You asked me to supply details of my course. This is an MPhil, which is being carried out at University College London and supervised by Linda Clare and Chris Barker. The course is of a 3 year duration, although the expectation is that the thesis will be written up by the end of my contract with this Trust in November 2002.

In the absence of Anne Fawcett, Mike Luckie, Clinical Psychologist, North East Essex Mental Health Trust, has agreed to be my practice supervisor. Please find written confirmation from Mike and also Linda Clare and Chris Barker that they have seen and approved the amended protocol.

With Best Wishes

Julie Scott
Research Psychologist



Memorandum

1 March 2001

to: Julie Scott, Kings Wood Centre

from: Catherine Hayes, Research Facilitator, 01206 22 8665

Scott, Grahame, Fawcett, Shivji and Clare
AE0006 Effectiveness of psychosocial interventions in early Dementia

The R&D Group considered the above project at our meeting of today. The above study is approved to proceed. The Group would like to pass on the following comments:

- Christopher Bridge commented that the study's topic was particularly important.
- The Group thanks you for contacting them about these changes in the study.

Good luck with your study and please do not hesitate to contact me if I can be of any assistance during this project. Please send me a copy of the completed research for our library when it is finished.



NORTH EAST ESSEX LOCAL RESEARCH ETHICS COMMITTEE
North Essex Health Authority
Turner Road
COLCHESTER, CO4 5JR

Our ref:

5th March 2001

Tel No: 01206 288531
Fax No: 01206 288501

OUR REF: MH169

Julie Scott
Research Psychologist
King's Wood Centre
Turner Road
Colchester
CO4 5JY

Dear Ms. Scott,

Our ref: MH169 Psychological Interventions in Early Dementia

Thank you for your letter dated 28th February 2001 detailing your revised proposal. Please ensure that our reference is enclosed on all future correspondence. This research is now given Local Research Ethics Committee approval to proceed under Chairman's Action.

You will no doubt realise that whilst the LREC has given approval for your project on ethical grounds, it is still necessary for you to obtain approval, if you have not already done so, from the Trust in which the work will be carried out. Please contact:

Mrs. Catherine Hayes, Research Facilitator, Trust HQ, North East Essex Mental Health Trust, 2 Boxted Road, Colchester CO4 5HG

Please advise the Committee of the research progress annually and when this research has been completed. If the research has not commenced within two years of this letter it will be necessary for the application to be resubmitted.

I wish you every success with your project.

Chair

North East Essex Local Research Ethics Committee

Cc Catherine Hayes



Essex County Council

North Essex Mental Health Partnership

NHS Trust



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PSYCHOLOGY DEPARTMENT

JS/EB

19 June 2001

Mr M Harrison
North East Essex Local Research
Ethics Committee
North East Essex Health Authority
Turner Road
Colchester
Essex CO4 5JR

Dear Mr Harrison

Re: MH169 Psychosocial Interventions in Early Dementia

The above study has now commenced. Now I have had the opportunity of putting what had been proposed into practise, there are a number of minor changes I would like to make, subject to your approval. I have also written to the Trust's R and D Group.

Patient and Partner Information Sheet

- I felt it would be more appropriate to have a Patient Information Sheet only (as opposed to Patient and Partner information sheet) for single clients proposing to participate in the groups. Please find a copy enclosed.
- I am registered for a PhD at University College London. Due to time constraints, I envisage carrying out the degree to MPhil level only. However, I felt I should also mention the PhD component
- I have also clarified that we will write to peoples GP's and share clinically relevant information with client's consultant, psychiatrists or other professionals in the Trust.

Please find a copy of the Information Sheets with the above two points incorporated.

GP Letter

As you are aware, the Trust name has changed. I would also like to include the date the course is running to and from on the letter.

Trust Headquarters, Cuton Hall Lane, Springfield, Chelmsford, Essex CM2 5PX
Tel: 01245 318400 Fax: 01245 318401 www.nemhpt.nhs.uk



INVESTOR IN PEOPLE

Please find enclosed a modified

- Patient Information Sheet
- Patient and Partner Information Sheet
- Standard G.P. Letter
- Schedule of questions for pre, post and follow up sessions (for use by clinicians).

I have also written to Martin Harrison, LREC regarding the above.

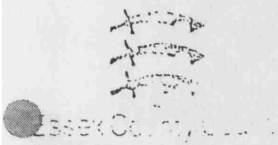
I look forward to hearing from you.

With best wishes

Yours sincerely

JULIE SCOTT
Research Psychologist

Copy: Dr Darren Mockler (Practice Supervisor)
Linda Clare
Dr Georgina Charlesworth



North Essex
Mental Health Partners...
NHS Trust



PSYCHOLOGY DEPARTMENT

JS/EB

5 September 2001

Mr M Harrison
North East Essex Local Research
Ethics Committee
North East Essex Health Authority
Turner Road
Colchester
Essex CO4 5JR

King's Wood Centre
Turner Road
COLCHESTER
Essex CO4 5JY

Tel: 01206 228718
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www.nemhpt.nhs.uk

Dear Mr Harrison

Re: MH169 Psychosocial Interventions in Early Dementia

I am writing to propose some changes to the above research, subject to your approval.

Brief Overview

The pilot study for the research was carried out in June to August 2000, with a Memory Group for clients and partners run at Colchester and a group for individuals run at Clacton. In June 2001, the main study commenced with a group for clients and partners at Colchester.

The groups have met with reasonable success and I recently presented findings to date at an annual PSIGE (Psychologist's Special Interest Group for Older Adults) Conference.

Rational Behind Proposed Changes

There has been a considerable amount of difficulty in recruiting participants for the groups. Many people do not seem comfortable with the idea of being in a group situation, which is an important finding in itself.

As I believe you are aware, the project is due to end in October 2001. I am therefore proposing to carry out the sessions with clients and partners on an individual as opposed to group basis. The sessions will follow a similar format containing elements of cognitive rehabilitation and cognitive behavioural techniques and the same measures will be administered pre and post intervention and as a follow up.

The design will be single case and therefore a control group will not be required because scores on questionnaires each participant obtains at the three collection parts will be compared. As before, other relevant information, such as medication status, will be recorded.

Trust Headquarters, Cuton Hall Lane, Springfield, Chelmsford, Essex CM2 5PX
Tel: 01245 318400 Fax: 01245 318401 www.nemhpt.nhs.uk



Please find enclosed a modified

- Patient Information Sheet
- Patient and Partner Information Sheet
- Standard G.P. Letter
- Schedule of questions for pre, post and follow up sessions (for use by clinicians).

I have also written to Catherine Hayes from the Trusts R and D Group regarding the above.

I look forward to hearing from you.

With best wishes

Yours sincerely

JULIE SCOTT
Research Psychologist

Copy: Dr Darren Mockler (Practice Supervisor)
Linda Clare
Dr Georgina Charlesworth



Essex County Council

North Essex Mental Health Partnership



NHS Trust

**CLINICAL PSYCHOLOGY &
NEUROPSYCHOLOGY DEPARTMENT**
JS/EB

17 December 2001

Mr M Harrison
North East Essex Local Research
Ethics Committee
North East Essex Health Authority
Turner Road
Colchester
Essex CO4 5JR

King's Wood Centre
Turner Road
COLCHESTER
Essex CO4 5JY

Tel: 01206
Fax: 01206 228901
www.nemhpt.nhs.uk

Dear Mr Harrison

Re: **MH169 Effectiveness of Psychosocial Interventions in Early Stage Dementia**

I am writing regarding the following two points.

1. I would like to change the Patient Information Sheet. Please find the new version enclosed. Whilst wishing to provide people with all the relevant information about the research, I feel the present information sheet is too complicated, and may both confuse and overwhelm potential participants.
2. As I believe you are aware, a difficulty with the research has been in recruiting a sufficient number of participants. I am currently carrying out an audit of Colchester Memory Clinic, which has been approved by the Trust's Audit Group. In addition to the questions I am considering, I also thought it would be useful to consider the number of clients who meet the criteria for the research. Please find the inclusion/exclusion criteria, which I would be looking at enclosed. The results would be included in the write up of the research, including my Master's Degree. I have also written to the Trust's Audit Group regarding this matter.

Thank you for your time. I look forward to hearing from you.

Yours sincerely

JULIE SCOTT
Research Psychologist

Copy: Catherine Hayes, Research Facilitator.

Enc

Trust Headquarters, Cuton Hall Lane, Springfield, Chelmsford, Essex CM2 5PX
Tel: 01245 318400 Fax: 01245 318401 www.nemhpt.nhs.uk 237



INVESTOR IN PEOPLE

Our ref: **NORTH EAST ESSEX LOCAL RESEARCH ETHICS COMMITTEE**
Colchester Primary Care Trust Building
Turner Road
COLCHESTER, CO4 5JR

Our ref: MH169

20th September 2001

Julie Scott
Research Psychologist
King's Wood Centre
Turner Road
Colchester CO4 5JY

Dear Ms.Scott,

Re: MH169 Psychological Interventions in Early Dementia

Thank you for your letter dated 5th September 2001 detailing the proposed amendment i.e. that participants will be seen individually and not on a group basis.

This has been considered by the Chairman and there is no objection to this amendment.

Yours sincerely

Martin Harrison
Chair
North East Essex Local Research Ethics Committee

Cc Catherine Hayes

NORTH EAST ESSEX LOCAL RESEARCH ETHICS COMMITTEE
Colchester Primary Care Trust Building
Turner Road
COLCHESTER, CO4 5JR

North Essex



Health Authority

Tel No: 01206 288531

Fax.No.01206 288501

E mail: NEELREC@ne-ha.nthames.nhs.uk

9th January 2002

Ms. Julie Scott
Research Psychologist
King's Wood Centre
Turner Road
Colchester

Dear Ms.Scott,

Re: MH169 Effectiveness of psychosocial interventions in early stage dementia

Thank you for your letter of 17th December 2001 and enclosed amendments.

I can see no problems with the amendments suggested. However, please ensure that any potential participants identified in the audit are either:

- 1.current clients of the service and
2. that the initial invitation to participate is made by a clinician already involved in the care of the client.

Yours sincerely

Martin Harrison
Chair
North East Essex Local Research Ethics Committee



Essex County Council

North Essex



Mental Health Partnership

NHS Trust

**CLINICAL PSYCHOLOGY &
NEUROPSYCHOLOGY DEPARTMENT**

JS/EB

16 January 2002

Mr M Harrison
North East Essex Local Research
Ethics Committee
North East Essex Health Authority
Turner Road
Colchester
Essex CO4 5JR

King's Wood Centre
Turner Road
COLCHESTER
Essex CO4 5JY

Dear Mr Harrison

Re: MH169 Effectiveness of Psychosocial Interventions in Early Stage Dementia

Thank you for your letter of the 9th January 2002.

I am writing to clarify your second point that the initial invitation to participate is made by a clinician already involved in the care of the client. As casenote audit is a standard practice within the service, clients will not be contacted. The audit has been approved by the Trust's Audit Group.

With regards to my research study I would, however, appreciate confirmation as to this procedure.

I also take it from your letter that you are happy with the changes to the Patient and Partner Information Sheet.

Yours sincerely

JULIE SCOTT
Research Psychologist

Copy: Catherine Hayes, Research Facilitator.
Judith Skargon, Trust Audit Group

Trust Headquarters, Cuton Hall Lane, Springfield, Chelmsford, Essex CM2 5PX
Tel: 01245 318400 Fax: 01245 318401 www.nemhpt.nhs.uk



INVESTOR IN PEOPLE

Appendix 4 – Patient and Partner Information Sheets

Psychosocial Interventions for People who have Memory Problems

Patient Information Sheet (Colchester)

At the Memory Clinic at King's Wood, we are investigating a range of ways of helping people with memory problems. The new drug treatments are available for some kinds of memory problems. There are also other ways of helping you cope with your memory problems. Previous research from other parts of the country does not give us clear results. So we decided to look in depth at what is helpful.

Memory Course

If you decide to enter the study, you will be offered a course. The course covers special training on how to deal with memory problems. We hope you will find what we offer helpful. However, we cannot say it will definitely help you with your memory problems. We hope you will enjoy it.

Topics covered in the course include:

1. types of memory
2. ways of coping with memory problems
3. the link between memory and mood.

The course will be for seven sessions. The sessions will take place weekly with myself. Each session will last about an hour. These can be at your home or at the King's Wood Centre, whichever you prefer. People who take part in the course will receive treatment from the Memory Clinic or Service as usual. We will describe what happens in your course and how you found it when we write the research up.

Questionnaires

In order to measure any changes which take place, you will be asked to complete some questions.

These will look at:

1. how your memory is working
2. how you view your memory problem

3. how you feel about yourself
4. your mood.
5. your relationship with others
6. how you feel your life is generally

We will ask you before and after the course. We will ask you again a few months later. We will also ask you about your goals. We will ask if our course helped with these.

We will complete a rating scale for you. This looks at if you have any symptoms. We will complete this before and after the course and a few months later.

Your patient notes

- 1) We will use scores from some questionnaires in your patient notes.
- 2) We will keep a copy of other questionnaires we do. We will put them in your patient notes.
- 3) We will write how you found the course in your patient notes.

We will record whether you are taking medication. We will also record if you are seeing any other services. This may be health, social services or voluntary services. We may know this from your patient notes. If not, we will ask you.

Sharing Information

If you decide to enter the study, we will write to your GP. We will do this before and after the course. We will also share certain information with the Consultant Psychiatrist or other people in our team. This is to help us work more effectively with you.

Writing up the research

We aim to write up and publish the research. The study will also be written up as a Masters of Philosophy (MPhil) or PhD degree. The degree is being carried out at University College London. It will be written up as a book or 'thesis.' It will probably be on a library shelf. Members of the public will be able to read it.

Summary

If you are happy, we will write up all the things we have talked about. The main things we will include are below:

- 1) A description of what we did in your course
- 2) Things you said during the course

- 3) How you said you found the course
- 4) Our observations about how you found the course
- 5) Scores from questionnaires you completed
- 6) Scores from some questionnaires in your patient notes
- 7) If you have been prescribed medication.
- 8) Any other services you are seeing.
- 9) Your age
- 10) Your gender.
- 11) Any diagnosis you have been given.
- 12) If others in your family have memory problems.
- 13) Any other relevant information

We will use initials or a number when we mention you. We will not use your name. People will not be able to tell who you are.

What if I don't want to take part?

You may not wish to take part. This is fine. You do not have to give a reason. The normal service you receive will not be affected.

Can I stop at any time?

You may decide to come out the study at any time without giving a reason. You may refuse to complete any of the questions you are asked. If you do ask to be removed from the study, your treatment at the Memory Clinic/with the Service will continue as before.

Contact Name: Julie Scott

Position: Research Psychologist

Address: Psychology Department, North Essex Mental Health Partnership NHS Trust, King's Wood Centre, Turner Road, Colchester, Essex, C04 5JY

Telephone number: 01206 228918

Psychosocial Interventions for People who have Memory Problems

Patient and Partner Information Sheet (Colchester).

At the Memory Clinic at King's Wood, we are investigating a range of ways of helping people with memory problems. The new drug treatments are available for some kinds of memory problems. There are also other ways of helping you cope with your memory problems. Previous research from other parts of the country does not give us clear results. So we decided to look in depth at what is helpful.

Memory Course

If you decide to enter the study, you will be offered a course. The course will cover special training on how to deal with memory problems. We hope you will find what we offer helpful. However, we can't say it will definitely help you with your memory problems. We hope you will enjoy it.

Topics covered in the course include:

1. types of memory
2. ways of coping with memory problems
3. the link between memory and mood

The course will be for seven sessions. The sessions will take place weekly with myself. These can be at your home or the King's Wood Centre, whichever you prefer. I will spend about forty to sixty minutes with each of you individually. I will then spend about half an hour with both of you together to talk about what we have discussed. The content of the sessions is similar for clients and partners. The sessions for partners look more at any difficulties the client has and how partners can help. It is also a chance for partners to discuss their own feelings about any difficulties or problems. People who take part the course will receive treatment from the Memory Clinic or Service as usual. We will describe what happens in the course and how you found it when we write the research up.

Questionnaires

In order to measure any changes which take place, you will be asked to complete some questions with a member of the team.

Patients will be asked to complete questions on:

1. how your memory is working
2. how you view your memory problem
3. how you feel about yourself
4. your mood.
5. your relationship with others
6. how you feel your life is generally

Partners will be asked to complete questions on:

1. how you feel your partner's memory is working
2. any difficulties your partner is experiencing
3. how you feel about yourself
4. your mood
5. your relationship with others
6. how you feel your life is generally

We will ask you before and after the course. We will ask you again a few months later. We will also ask you about your goals. We will ask if our course helped with these.

We will also complete a rating scale for patients. This looks at if you have any symptoms. We will complete this before and after the course and a few months later.

Your patient notes

- 1) We will use scores from some questionnaires in your patient notes.
- 2) We will keep a copy of other questionnaires we do. We will put them in your patient notes.
- 3) Patients' partners will be asked to complete some questions about them. These will be put in the patient notes.
- 4) We will write how you and your partner found the course in the patient notes.

you are seeing any other services. This may be health, social services or voluntary services. We may know this from your patient notes. If not, we will ask you.

Sharing Information

If you decide to enter the study, we will write to our client's GP. We will do this before and after the study. We will also share certain information with the Consultant Psychiatrist or other people in our team. This is to help us work more effectively with you.

Writing up the research

We aim to write up and publish the research. The study will also be written up as a Masters of Philosophy (MPhil) or PhD degree. The degree is being carried out at University College London. It will be written up as a book or 'thesis.' It will probably be on a library shelf. Members of the public will be able to read it.

If you are happy, we will write up all the things we have talked about. The main things we will include are below:

- 1) A description of what we did in the course
- 2) Things you both said during the course
- 3) How you both said you found the course
- 4) Our observations about how you found the course
- 5) Scores from questionnaires you completed
- 6) Scores from questionnaires in the patient notes.
- 7) Any medication the client has been prescribed
- 8) Any other services you are seeing
- 9) Your age
- 10) Your gender
- 11) Any diagnosis the client has been given
- 12) If others in the client's family have memory problems
- 13) Any other relevant information.

We will use initials or a number when we mention you. We will not use your name. People will not be able to tell who you are.

What if I don't want to take part?

You may not wish to take part. This is fine. You do not have to give a reason. The normal service you receive will not be affected.

Can I stop at any time?

You may decide to come out the study at any time without giving a reason. You may refuse to complete any of the questions you are asked. If you do ask to be removed from the study, your treatment at the Memory Clinic/with the Service will continue as before.

Contact Name: Julie Scott

Position: Research Psychologist

Address: Psychology Department, King's Wood Centre, Turner Road,
Colchester, Essex, C04 5JY

Telephone: 01206 228918

Psychosocial Interventions for People who have Memory Problems

Patient and Partner Information Sheet (Clacton).

At the Memory Clinic at King's Wood, we are investigating a range of ways of helping people with memory problems. The new drug treatments are available for some kinds of memory problems. There are also other ways of helping you cope with your memory problems. Previous research from other parts of the country does not give us clear results. So we decided to look in depth at what is helpful.

Memory Course

If you decide to enter the study, you will be offered a course. The course will cover special training on how to deal with memory problems. We hope you will find what we offer helpful. However, we can't say it will definitely help you with your memory problems. We hope you will enjoy it.

Topics covered in the course include.

1. types of memory
2. ways of coping with memory problems
3. the link between memory and mood.

The course will be for seven sessions. The sessions will take place weekly with myself. These can be at your home or Clacton Hospital, whichever you prefer. I will spend about forty to sixty minutes with each of you individually. I will then spend about half an hour with both of you together to talk about what we have discussed. The content of the sessions is similar for clients and partners. The sessions for partners look more at any difficulties the client has and how partners can help. It is also a chance for partners to discuss their own feelings about any difficulties or problems. People who take part the course will receive treatment from the Memory Clinic or Service as usual. We will describe what happens in the course and how you found it when we write the research up.

3. how you feel about yourself
4. your mood.
5. your relationship with others
6. how you feel your life is generally

We will ask you before and after the course. We will ask you again a few months later. We will also ask you about your goals. We will ask if our course helped with these.

We will complete a rating scale for you. This looks at if you have any symptoms. We will complete this before and after the course and a few months later.

Your patient notes

- 1) We will use scores from some questionnaires in your patient notes.
- 2) We will keep a copy of other questionnaires we do. We will put them in your patient notes.
- 3) We will write how you found the course in your patient notes.

We will record whether you are taking medication. We will also record if you are seeing any other services. This may be health, social services or voluntary services. We may know this from your patient notes. If not, we will ask you.

Sharing Information

If you decide to enter the study, we will write to your GP. We will do this before and after the course. We will also share certain information with the Consultant Psychiatrist or other people in our team. This is to help us work more effectively with you.

Writing up the research

We aim to write up and publish the research. The study will also be written up as a Masters of Philosophy (MPhil) or PhD degree. The degree is being carried out at University College London. It will be written up as a book or 'thesis.' It will probably be on a library shelf. Members of the public will be able to read it.

Summary

If you are happy, we will write up all the things we have talked about. The main things we will include are below:

- 1) A description of what we did in your course
- 2) Things you said during the course

- 3) How you said you found the course
- 4) Our observations about how you found the course
- 5) Scores from questionnaires you completed
- 6) Scores from some questionnaires in your patient notes
- 7) If you have been prescribed medication.
- 8) Any other services you are seeing.
- 9) Your age
- 10) Your gender.
- 11) Any diagnosis you have been given.
- 12) If others in your family have memory problems.
- 13) Any other relevant information

We will use initials or a number when we mention you. We will not use your name. People will not be able to tell who you are.

What if I don't want to take part?

You may not wish to take part. This is fine. You do not have to give a reason. The normal service you receive will not be affected.

Can I stop at any time?

You may decide to come out the study at any time without giving a reason. You may refuse to complete any of the questions you are asked. If you do ask to be removed from the study, your treatment at the Memory Clinic/with the Service will continue as before.

Contact Name: Julie Scott

Position: Research Psychologist

Address: Psychology Department, North Essex Mental Health Partnership NHS Trust, King's Wood Centre, Turner Road, Colchester, Essex, C04 5JY

Telephone number: 01206 228918

Psychosocial Interventions for People who have Memory Problems

Patient Information Sheet (Clacton)

At the Memory Clinic at King's Wood, we are investigating a range of ways of helping people with memory problems. The new drug treatments are available for some kinds of memory problems. There are also other ways of helping you cope with your memory problems. Previous research from other parts of the country does not give us clear results. So we decided to look in depth at what is helpful.

Memory Course

If you decide to enter the study, you will be offered a course. The course covers special training on how to deal with memory problems. We hope you will find what we offer helpful. However, we cannot say it will definitely help you with your memory problems. We hope you will enjoy it.

Topics covered in the course include:

1. types of memory
2. ways of coping with memory problems
3. the link between memory and mood.

The course will be for seven sessions. The sessions will take place weekly with myself. Each session will last about an hour. These can be at your home or Clacton Hospital, whichever you prefer. People who take part in the course will receive treatment from the Memory Clinic or Service as usual. We will describe what happens in your course and how you found it when we write the research up.

Questionnaires

In order to measure any changes which take place, you will be asked to complete some questions.

These will look at:

1. how your memory is working
2. how you view your memory problems

Questionnaires

In order to measure any changes which take place, you will be asked to complete some questions with a member of the team.

Patients will be asked to complete questions on:

1. how your memory is working
2. how you view your memory problem
3. how you feel about yourself
4. your mood.
5. your relationship with others
6. how you feel your life is generally

Partners will be asked to complete questions on:

1. how you feel your partner's memory is working
2. any difficulties your partner is experiencing
3. how you feel about yourself
4. your mood
5. your relationship with others
6. how you feel your life is generally

We will ask you before and after the course. We will ask you again a few months later. We will also ask you about your goals. We will ask if our course helped with these.

We will also complete a rating scale for patients. This looks at if you have any symptoms. We will complete this before and after the course and a few months later.

Your patient notes

- 1) We will use scores from some questionnaires in your patient notes.
- 2) We will keep a copy of other questionnaires we do. We will put them in your patient notes.
- 3) Patients' partners will be asked to complete some questions about them. These will be put in the patient notes.
- 4) We will write how you and your partner found the course in the patient notes.

We will record whether you are taking medication. We will also record if you are seeing any other services. This may be health, social services or voluntary services. We may know this from your patient notes. If not, we will ask you.

Sharing Information

If you decide to enter the study, we will write to our client's GP. We will do this before and after the study. We will also share certain information with the Consultant Psychiatrist or other people in our team. This is to help us work more effectively with you.

Writing up the research

We aim to write up and publish the research. The study will also be written up as a Masters of Philosophy (MPhil) or PhD degree. The degree is being carried out at University College London. It will be written up as a book or 'thesis.' It will probably be on a library shelf. Members of the public will be able to read it.

If you are happy, we will write up all the things we have talked about. The main things we will include are below:

- 1) A description of what we did in the course
- 2) Things you both said during the course
- 3) How you both said you found the course
- 4) Our observations about how you found the course
- 5) Scores from questionnaires you completed.
- 6) Scores from questionnaires in the patient notes.
- 7) Any medication the client has been prescribed
- 8) Any other services you are seeing
- 9) Your age
- 10) Your gender
- 11) Any diagnosis the client has been given
- 12) If others in the client's family have memory problems
- 13) Any other relevant information.

We will use initials or a number when we mention you. We will not use your name. People will not be able to tell who you are.

What if I don't want to take part?

You may not wish to take part. This is fine. You do not have to give a reason. The normal service you receive will not be affected.

Can I stop at any time?

You may decide to come out the study at any time without giving a reason. You may refuse to complete any of the questions you are asked. If you do ask to be removed from the study, your treatment at the Memory Clinic/with the ~~Appendix 5 - Consent Forms~~ will continue as before.

Contact Name: Julie Scott

Position: Research Psychologist

Address: Psychology Department, King's Wood Centre, Turner Road, Colchester, Essex, C04 5JY

Telephone: 01206 228918

Appendix 5 – Consent Forms

PATIENT CONSENT FORM

PROJECT NAME Psychosocial Interventions for People with Memory Problems

Please complete this form, if you wish to take part in this project.

Who has spoken to you about this project? Dr/Mr/Ms.....

	Please tick box	
	YES	NO
Have you been told that you may withdraw from the project:		
a. At any time		
b. Without giving a reason		
c. Without affecting the services you receive from the Trust?		
Have you read the Information Sheet for this project?		
Do you understand that you may refuse to answer any question without giving a reason?		
Are you satisfied with the answers given to any questions you have asked about the project?		
Have you received enough information?		
Do you agree to take part in this project?		

Signed

Date

NAME in BLOCK LETTERS.....

Witnessed by.....

Date

NAME in BLOCK LETTERS.....

PARTICIPANT CONSENT FORM

PROJECT NAME Psychosocial Interventions for People with Memory Problems

Please complete this form, if you wish to take part in this project.

Who has spoken to you about this project? Dr/Mr/Ms.....

Please tick
box

YES NO

Have you been told that you may withdraw from the project:

- a. At any time
- b. Without giving a reason
- c. Without affecting the services you receive from the Trust?

<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------

Have you read the Information Sheet for this project?

<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------

Do you understand that you may refuse to answer any question without giving a reason?

<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------

Are you satisfied with the answers given to any questions you have asked about the project?

<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------

Have you received enough information?

<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------

Do you agree to take part in this project?

<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------

Signed

Date

NAME in BLOCK LETTERS.....

Witnessed by.....

Date

NAME in BLOCK LETTERS.....

Appendix 6 – Letters to GPs

Standard G.P. letter for Patients only.

Dear Dr -,

Re: -----

I am writing to inform you that --- has agreed to participate in a psychoeducational course which will address ways of helping with memory problems. The courses are the core component of a research project (which has been approved by LREC and the Trust's R and D group) investigating the effectiveness of psychosocial interventions for people diagnosed as being in the early stages of dementia. The course will take place from ---- to ---- and involve individual weekly sessions of approximately one hour. Measures will be administered pre and post intervention, and also as a follow-up approximately three months later. During these sessions ---'s targets relating to memory will be explored and it will be determined whether these were met by the course.

--- will continue to receive standard treatment from the North Essex Mental Health Trust Partnership NHS Trust. --- is obviously free to withdraw from the study at any time, with no effect on the usual treatment received from the North Essex Mental Health Partnership Trust.

Yours sincerely,

Julie Scott
Research Psychologist

Standard G.P. letter for Patients and Partners

Dear Dr -,

Re: -----

I am writing to inform you that --- has agreed to participate in a psychoeducational course which will address ways of helping with memory problems. The courses are the core component of a research project (which has been approved by LREC and the Trust's R and D group) investigating the effectiveness of psychosocial interventions for people diagnosed as being in the early stages of dementia. The course will take place from ---- to ---- and involve individual and joint weekly sessions with clients and their partners, totalling approximately two hours. Measures will be administered pre and post intervention, and also as a follow-up approximately three months later. During these sessions ---'s targets relating to memory will be explored and it will be determined whether these were met by the course.

--- will continue to receive standard treatment from the North Essex Mental Health Trust Partnership NHS Trust. --- is obviously free to withdraw from the study at any time, with no effect on the usual treatment received from the North Essex Mental Health Partnership Trust.

Yours sincerely,

Julie Scott
Research Psychologist

Appendix 7 – Quality of Life and Family Functioning Question (Group C)

Do you feel able to talk to your family about your memory problems?

Always (5) Often (4) Sometimes (3) Rarely (2) Never (1)

Do you feel able to talk to your family about your partner's memory problems?

Always (5) Often (4) Sometimes (3) Rarely (2) Never (1)

How happy are you with your life now?

Very unhappy (1) Quite unhappy (2) Neither happy or unhappy (3)

Quite Happy (4) Very happy (5)

Appendix 8 – Measures

Hospital Anxiety and Depression Scale (HADS)



Name: _____ Date: _____

Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings he or she will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel. Read each item below and **underline the reply** which comes closest to how you have been feeling in the past week. Ignore the numbers printed at the edge of the questionnaire.

Don't take too long over your replies, your immediate reaction to each item will probably be more accurate than a long, thought-out response.

FOLD HERE

FOLD HERE

A	D			A	D
3		I feel tense or 'wound up'	I feel as if I am slowed down	3	
2		Most of the time	Nearly all the time	2	
1		A lot of the time	Very often	1	
0		From time to time, occasionally	Sometimes	0	
		Not at all	Not at all		
0		I still enjoy the things I used to enjoy	I get a sort of frightened feeling like 'butterflies' in the stomach	0	
1		Definitely as much	Not at all	1	
2		Not quite so much	Occasionally	2	
3		Only a little	Quite often	3	
		Hardly at all	Very often		
3		I get a sort of frightened feeling as if something awful is about to happen	I have lost interest in my appearance	3	
2		Very definitely and quite badly	Definitely	2	
1		Yes, but not too badly	I don't take as much care as I should	1	
0		A little, but it doesn't worry me	I may not take quite as much care	0	
		Not at all	I take just as much care as ever		
0		I can laugh and see the funny side of things	I feel restless as if I have to be on the move	3	
1		As much as I always could	Very much indeed	2	
2		Not quite so much now	Quite a lot	1	
3		Definitely not so much now	Not very much	0	
		Not at all	Not at all		
3		Worrying thoughts go through my mind	I look forward with enjoyment to things	0	
2		A great deal of the time	As much as I ever did	1	
1		A lot of the time	Rather less than I used to	2	
0		Not too often	Definitely less than I used to	3	
		Very little	Hardly at all		
3		I feel cheerful	I get sudden feelings of panic	3	
2		Never	Very often indeed	2	
1		Not often	Quite often	1	
0		Sometimes	Not very often	0	
		Most of the time	Not at all		
0		I can sit at ease and feel relaxed	I can enjoy a good book or radio or television programme	0	
1		Definitely	Often	1	
2		Usually	Sometimes	2	
3		Not often	Not often	3	
		Not at all	Very seldom		

Now check that you have answered all the questions

TOTAL

This form is printed in green. Any other colour is an unauthorized photocopy.

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ROSENBERG SELF-ESTEEM SCALE



Name:

Date: Record Number:

Here is a list of statements dealing with your general feelings about yourself. If you **agree** with the statement, circle A. If you **strongly agree**, circle SA. If you **disagree**, circle D. If you **strongly disagree**, circle SD. Thank you.

	1 Strongly agree	2 Agree	3 Disagree	4 Strongly disagree
1. On the whole, I am satisfied with myself.	SA	A	D	SD
2. At times I think I am no good at all.	SA	A	D	SD
3. I feel that I have a number of good qualities.	SA	A	D	SD
4. I am able to do things as well as most other people.	SA	A	D	SD
5. I feel I do not have much to be proud of.	SA	A	D	SD
6. I certainly feel useless at times.	SA	A	D	SD
7. I feel that I'm a person of worth, at least on an equal plane with others.	SA	A	D	SD
8. I wish I could have more respect for myself.	SA	A	D	SD
9. All in all, I am inclined to feel that I am a failure.	SA	A	D	SD
10. I take a positive attitude toward myself.	SA	A	D	SD

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GENERALIZED SELF-EFFICACY SCALE



Name:

Date: Record Number:

	Not at all true	Barely true	Moderately true	Exactly true
1. I can always manage to solve difficult problems if I try hard enough.	1	2	3	4
2. If someone opposes me, I can find <i>ways</i> and <i>means</i> to get what I want.	1	2	3	4
3. It is easy for me to stick to my aims and accomplish my goals.	1	2	3	4
4. I am confident that I could deal efficiently with unexpected events.	1	2	3	4
5. Thanks to my resourcefulness, I know how to handle unforeseen situations.	1	2	3	4
6. I can solve most problems if I invest the necessary effort.	1	2	3	4
7. I can remain calm when facing difficulties because I can rely on my coping abilities.	1	2	3	4
8. When I am confronted with a problem, I can usually find several solutions.	1	2	3	4
9. If I am in a bind, I can usually think of something to do.	1	2	3	4
10. No matter what comes my way, I'm usually able to handle it.	1	2	3	4

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THE MEMORY AWARENESS RATING SCALE (MARS)

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Publication

The MARS is currently being prepared for publication. Please contact the author for further details.

THE MEMORY AWARENESS RATING SCALE (MARS)

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THE MEMORY AWARENESS RATING SCALE (MARS)

ABOUT THE MARS

Overview of the MARS

The Memory Awareness Rating Scale (MARS) assesses memory awareness in two domains:

- ◆ **The Memory Functioning Scale (MARS-MFS)** assesses subjective views of memory functioning. The MARS-MFS has parallel self-report and informant scales and asks for subjective ratings of memory functioning in relation to specified aspects of everyday memory functioning. Ratings are made on a 0 - 4 scale where 0 = never and 4 = always. The scale is usually administered in an interview format, but a version in questionnaire format is also provided for use by informants.
- ◆ **The Memory Performance Scale (MARS-MPS)** assesses views of memory performance on specific aspects of memory functioning following direct experience in each case of an analogue task assessing the given aspect of memory functioning. Ratings are made on a 0 - 4 scale where 0 = very poor and 4 = very good. The MARS-MPS is administered together with the appropriate version of the Rivermead Behavioural Memory Test (RBMT). As each subtest is completed, the participant is asked to rate his or her performance on that subtest, which constitutes the analogue task. These tasks are analogues of the real-life situations covered in the MFS, thus allowing a comparison of responses on the two scales.

The scales can be used individually or as a complete set, depending on the aims of assessment. Partners or other carers giving informant ratings of participants may also evaluate their own memory functioning using the MARS. This allows an assessment of the accuracy of their own self-ratings and may be indicative of particular response patterns that influence their ratings of participants.

Selecting the appropriate version of the RBMT

For people who have, or are assumed to have, memory impairments, the standard RBMT is used. For those who are not thought to have memory impairments, the extended RBMT (RBMT-E) is used. Both versions assess performance in the same areas of everyday memory functioning, but the latter is more demanding. These areas are analogues of those assessed by the questions in the MARS-MFS. Note that when using the RBMT-E, participants should also be assessed on the National Adult Reading Test (NART), as this is necessary for the conversion of raw scores to profile scores on some subtests. For each subtest, the profile score should be recorded on the MARS score sheet. RBMT-E profile scores are based on a 0 - 4 scale and require no adjustment. RBMT standardised profile scores are based on a 0 - 2 scale and require conversion to a 0 - 4 scale; to make this conversion, the tester should multiply the standardised profile score by 2 (i.e. an SPS of 0 remains the same, an SPS of 1 is listed as 2, and an SPS of 2 is listed as 4).

THE MEMORY AWARENESS RATING SCALE (MARS)

PSYCHOMETRIC PROPERTIES OF THE MARS

Psychometric properties of the scale have been assessed in a small-scale pilot study investigating internal consistency, test-retest reliability, and criterion validity. Data was obtained from 15 couples where one partner had a diagnosis of early-stage Alzheimer's disease (the 'participant').

Internal consistency

Internal consistency of the MFS was assessed using data from participant self-rating, partner rating of the participant, and partner self-rating, a total of 45 responses, and yielded Cronbach's alpha of .94.

Internal consistency of the MPS was assessed using self-ratings by participants and informants, a total of 30 responses, and yielded Cronbach's alpha of .93.

Test-retest reliability

Test-retest reliability was evaluated by reassessing 10 participants and 9 partners after a one week interval. For the MFS, test-retest reliability was .91 for participant self-rating, .9 for partner rating of the participant, and .63 for partner self-rating. For the MPS, test-retest reliability was .97 for participant self-rating and .73 for partner self-rating. Prior administration of the MPS affects partners ratings of their own functioning on reassessment.

Criterion validity

Criterion validity of the MARS-MFS was evaluated in relation to the Memory Insight Questionnaire (MIQ; Markova, 1997) and the Memory Symptoms Questionnaire (MSQ; Kapur & Pearson, 1983), using participant self-ratings and partner ratings of participants from 12 couples. The MSQ relates solely to memory functioning while the MIQ asks about broader domains of functioning. The correlations are summarised below.

	MSQ	MIQ
MFS participant self-rating	-.71	-.74
MFS informant rating of participant	-.7	-.56

THE MEMORY AWARENESS RATING SCALE (MARS)

USING THE MARS TO EVALUATE AWARENESS OF MEMORY FUNCTIONING

Responses on the MFS provide a clinically-useful indication of participants' and informants' perceptions of memory functioning, and responses on the MPS provide an indication of the impact of direct experience on self-ratings. For a more detailed examination of awareness, and particularly for research purposes, discrepancy scores can be calculated.

Memory awareness is evaluated by examination of

- ♦ discrepancies between participant and informant responses on the Memory Functioning Scale (MFS-D rating). Informant ratings are subtracted from participant ratings.
- ♦ discrepancies between participant responses on the Memory Performance Scale and actual task performance on the relevant RBMT or RBMT-E subtest (MPS-D rating). Profile scores are subtracted from participant ratings.

Discrepancy scores are calculated on a question-by-question basis and summed across all items within the relevant scale to give a total discrepancy score. Discrepancies may be positive, where the participant ratings are higher than the informant ratings/test scores, or negative, where the participant ratings are lower than the informant ratings/test scores.

In a study using the MARS to explore the influence of memory awareness on the outcome of a cognitive rehabilitation intervention for people with early-stage Alzheimer's disease, and controlling for severity of dementia, negative or low discrepancy scores on the MARS were associated with better response to intervention.

MEMORY AWARENESS RATING SCALE

Memory Functioning Scale - Self-report version (MARS-MFS-S)

I'm going to give you some examples of everyday situations where you might need to use your memory. I want you to think about your own memory, as it is now, and tell me how you think you would manage in that situation. I want you to choose the answer which best describes how you would do. The answers are on the card here. These are the situations:

1. You meet someone and are told their name. Later on you meet them again, and you need to remember their name.
2. You have made an appointment. You need to remember to go along.
3. You have promised to do something later in the day. You need to remember to do it at the right time.
4. You have got a set of items to sort out, some of which you have seen before and some of which are new to you. You need to pick out the ones you have seen before.
5. You hear a news item on the radio.
(a) One of your family comes in at the end and asks you what was said.
(b) Later on - say half an hour later - someone else asks you what you heard.
6. You meet up with a group of people. Some of them you've met before, others you haven't. You need to recognise which ones you've met before.
7. You go to a new building and you are learning to find your way around. Someone shows you a short route which you will need to remember.
(a) You need to retrace the route immediately
(b) You need to retrace the route again later on - say half an hour later.
8. You have been given a message to deliver to someone. You need to remember to give that person the message when you see them.
(a) You see them right away.
(b) You see them later on.
9. You are being asked to give some information about yourself, such as your age, address, date of birth and so on, and to answer a few basic general knowledge questions.
10. Someone asks you for today's date.

MEMORY AWARENESS RATING SCALE

Memory Functioning Scale - Informant version (MARS-MFS-I)

I'm going to give you some examples of everyday situations where a person might need to use his/her memory. I want you to think about your partner's memory, as it is now, and tell me how you think he/she would manage in that situation. I want you to choose the answer on the card which best describes how he/she would do. These are the situations:

1. S/he meets someone and is told their name. Later on s/he meets them again, and needs to remember their name.
2. S/he has made an appointment and needs to remember to go along.
3. S/he has promised to do something later in the day, and needs to remember to do it at the right time.
4. S/he has got a set of items to sort out, some of which s/he has seen before and some of which are new to her/him. S/he needs to pick out the ones s/he has seen before.
5. S/he hears a news item on the radio.
(a) One of the family comes in at the end and asks what was said.
(b) Later on - say half an hour later - someone else asks what was said.
6. S/he meets up with a group of people. Some of them s/he has met before, others are new. S/he needs to recognise which ones s/he has met before.
7. S/he goes to a new building and is learning to find the way around. Someone shows her/him a short route which s/he needs to remember.
(a) S/he needs to retrace the route immediately
(b) S/he needs to retrace the route again later on - say half an hour later.
8. S/he has been given a message to deliver to someone and needs to remember to give that person the message when s/he sees them.
(a) S/he sees them right away.
(b) S/he sees them later on.
9. S/he is being asked to give some information about her/himself, such as age, address, date of birth and so on, and to answer a few basic general knowledge questions.
10. Someone asks her/him for today's date.

MEMORY AWARENESS RATING SCALE

Memory Performance Scale (MARS-MPS) - *for use in conjunction with RBMT or RBMT-E*

We are going to do a memory task that looks at how your memory works in everyday situations. The task has several different parts. As we go through the task and finish each part, I'm going to ask you to tell me how you think you have done on that particular part. I want you to choose the answer that best matches how you think you have done. The answers are on the card here.

1. Story - immediate

I read you a short story and asked you to remember as much as you could from it.

2. Picture recognition

I asked you to pick out those of the pictures you had seen earlier on.

3. Route - immediate

I asked you to watch me tracing a short route around the room and then asked you to follow the same route.

4. Message - immediate

I also asked you to deliver a message along the way.

5. Face recognition

I asked you to pick out those of the faces you had seen earlier on.

6. Orientation

I asked you for some information about yourself and there were a few general knowledge questions to answer as well.

7. Date

I also asked you for today's date.

8. Appointment

I asked you to remember to ask me a question when the timer sounded.

9. Story - delayed

I asked you how much you could remember of the story I read you earlier on.

10. Route - delayed

I asked you to see how much you could remember of the route I showed you earlier.

11. Message - delayed

I also wanted to see if you would remember to deliver the message along the way.

12. Names

I asked you for the name of the person whose picture I showed you earlier.

13. Belonging

I asked you to remind me to give you back your [*name of item*] which I had put away, and also to remind me where I had put it.

MARS: SCORE SHEET FOR INTERVIEW ADMINISTRATION

Name/code:

Date:

Date of birth:

RBMT version: Standard Extended
 a b c d 1 2

Q	MFS-S Rating	MFS-I Rating	MFS-D (S-I)	Q	MPS Rating	RBMT adjusted SPS or RBMT-E Profile Score	MPS-D (MPS - SPS)
1	0 1 2 3 4	0 1 2 3 4		12	0 1 2 3 4	0 1 2 3 4	
2	0 1 2 3 4	0 1 2 3 4		8	0 1 2 3 4	0 1 2 3 4	
3	0 1 2 3 4	0 1 2 3 4		13	0 1 2 3 4	0 1 2 3 4	
4	0 1 2 3 4	0 1 2 3 4		2	0 1 2 3 4	0 1 2 3 4	
5a	0 1 2 3 4	0 1 2 3 4		1	0 1 2 3 4	0 1 2 3 4	
5b	0 1 2 3 4	0 1 2 3 4		9	0 1 2 3 4	0 1 2 3 4	
6	0 1 2 3 4	0 1 2 3 4		5	0 1 2 3 4	0 1 2 3 4	
7a	0 1 2 3 4	0 1 2 3 4		3	0 1 2 3 4	0 1 2 3 4	
7b	0 1 2 3 4	0 1 2 3 4		10	0 1 2 3 4	0 1 2 3 4	
8a	0 1 2 3 4	0 1 2 3 4		4	0 1 2 3 4	0 1 2 3 4	
8b	0 1 2 3 4	0 1 2 3 4		11	0 1 2 3 4	0 1 2 3 4	
9	0 1 2 3 4	0 1 2 3 4		6	0 1 2 3 4	0 1 2 3 4	
10	0 1 2 3 4	0 1 2 3 4		7	0 1 2 3 4	0 1 2 3 4	
Total				Total			

MEMORY AWARENESS RATING SCALE

Memory Functioning Scale - Informant Version (MARS-MFS-I)

SCORE SHEET

Below are some examples of everyday situations where a person might need to use his/her memory.

Please think about your partner's memory, as it is now, and rate how you think he/she would manage in that situation.

SITUATION	FREQUENCY 0 = never 1 = rarely 2 = sometimes 3 = often 4 = always
1. S/he meets someone and is told their name. Later on s/he meets them again, and needs to remember their name.	0 1 2 3 4
2. S/he has made an appointment and needs to remember to go along.	0 1 2 3 4
3. S/he has promised to do something later in the day, and needs to remember to do it at the right time.	0 1 2 3 4
4. S/he has got a set of items to sort out, some of which s/he has seen before and some of which are new to her/him. S/he needs to pick out the ones s/he has seen before.	0 1 2 3 4
5. S/he hears a news item on the radio. (a) One of the family comes in at the end and asks what was said. (b) Later on - say half an hour later - someone else asks what was said.	0 1 2 3 4 0 1 2 3 4
6. S/he meets up with a group of people. Some of them s/he has met before, others are new. S/he needs to recognise which ones s/he has met before.	0 1 2 3 4
7. S/he goes to a new building and is learning to find the way around. Someone shows her/him a short route which s/he needs to remember. (a) S/he needs to retrace the route immediately (b) S/he needs to retrace the route again later on - say half an hour later.	0 1 2 3 4 0 1 2 3 4
8. S/he has been given a message to deliver to someone and needs to remember to give that person the message when s/he sees them. (a) S/he sees them right away. (b) S/he sees them later on.	0 1 2 3 4 0 1 2 3 4
9. S/he is being asked to give some information about her/himself, such as age, address, date of birth and so on, and to answer a few basic general knowledge questions.	0 1 2 3 4
10. Someone asks her/him for today's date.	0 1 2 3 4

I think I would be able to do this:



Always



Often



Sometimes



Rarely



Never

**I think my partner would be able to
do this:**



Always



Often



Sometimes



Rarely



Never

I think my score on this was:



Very good



Good



Alright



Poor



Very poor

Family APGAR Questionnaire

	Almost always	Some of the time	Hardly ever
I am satisfied with the help that I receive from my family when something is troubling me			
I am satisfied with the way my family discusses items of common interest and shares problem solving with me			
I find that my family accepts my wishes to take on new activities or make changes in my life-style			
I am satisfied with the way my family expresses affection and responds to my feelings such as anger, sorrow or love			
I am satisfied with the amount of time my family and I spend together			

Assessment Interval:

Specify: _____ wks.

Total Score: _____

Part I : Symptomatology

A. Paranoid and Delusional Ideation

Score

1. "People Are Stealing Things" Delusion ☐
 - (0) = Not present
 - (1) = Delusion that people are hiding objects
 - (2) = Delusion that people are coming into the home and hiding objects or stealing objects
 - (3) = Talking and listening to people coming into the home
2. "One's House Is Not One's Home" Delusion ☐
 - (0) = Not present
 - (1) = Conviction that the place in which one is residing is not one's home (e.g., packing to go home; complaints, while at home, of "take me home")
 - (2) = Attempt to leave domiciliary to go home
 - (3) = Violence in response to attempts to forcibly restrict exit
3. "Spouse (or Other Caregiver) Is an Imposter" Delusion ☐
 - (0) = Not present
 - (1) = Conviction that spouse (or other caregiver) is an imposter
 - (2) = Anger toward spouse (or other caregiver) for being an imposter
 - (3) = Violence towards spouse (or other caregiver) for being an imposter
4. "Delusion of Abandonment" (e.g., to an Institution) ☐
 - (0) = Not present
 - (1) = Suspicion of caregiver plotting abandonment or institutionalisation (e.g., on telephone)
 - (2) = Accusation of a conspiracy to abandon or institutionalise
 - (3) = Accusation of impending or immediate desertion or institutionalisation
5. "Delusion of Infidelity" ☐
 - (0) = Not present
 - (1) = Conviction that spouse and/or children and/or other caregivers are unfaithful
 - (2) = Anger toward spouse, relative, or other caregiver for infidelity
 - (3) = Violence toward spouse, relative, or other caregiver for supposed infidelity
6. "Suspiciousness/Paranoia" (other than above) ☐
 - (0) = Not present
 - (1) = Suspicious (e.g., hiding objects that he/she later may be unable to locate)
 - (2) = Paranoid (i.e., fixed conviction with respect to suspicions and/or anger as a result of suspicions)
 - (3) = Violence as a result of suspicions

Unspecified? _____

Describe _____

7. Delusions (other than above) ☐
 - (0) = Not present
 - (1) = Delusional
 - (2) = Verbal or emotional manifestations as a result of delusions
 - (3) = Physical actions or violence as a result of delusions

Unspecified? _____

Describe _____

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Total Score (A) ☐

B. Hallucinations

8. Visual Hallucinations ☐
 - (0) = Not present
 - (1) = Vague; not clearly defined
 - (2) = Clearly defined hallucinations of objects or persons (e.g., sees other people at the table)
 - (3) = Verbal or physical actions or emotional responses to the hallucinations
9. Auditory Hallucinations ☐
 - (0) = Not present
 - (1) = Vague; not clearly defined
 - (2) = Clearly defined hallucinations of words or phrases
 - (3) = Verbal or physical actions or emotional response to the hallucinations
10. Olfactory Hallucinations ☐
 - (0) = Not present
 - (1) = Vague; not clearly defined
 - (2) = Clearly defined
 - (3) = Verbal or physical actions or emotional responses to the hallucinations
11. Haptic Hallucination ☐
 - (0) = Not present
 - (1) = Vague; not clearly defined
 - (2) = Clearly defined
 - (3) = Verbal or physical actions or emotional responses to the hallucinations
12. Other Hallucinations ☐
 - (0) = Not present
 - (1) = Vague; not clearly defined
 - (2) = Clearly defined
 - (3) = Verbal or physical actions or emotional responses to the hallucination

Unspecified? _____

Describe _____

Total Score (B) ☐

C. Activity Disturbances

13. Wandering: Away From Home or Caregiver ☐
 - (0) = Not present
 - (1) = Somewhat, but not sufficient to necessitate restraint
 - (2) = Sufficient to require restraint
 - (3) = Verbal or physical actions or emotional responses to attempts to prevent wandering
14. Purposeless Activity (Cognitive Abulia) ☐
 - (0) = Not present
 - (1) = Repetitive, purposeless activity (e.g., opening and closing pocketbook, packing and unpacking clothing, repeatedly putting on and removing clothing, opening and closing drawers, insistent repeating of demands or questions)
 - (2) = Pacing or other purposeless activity sufficient to require restraint
 - (3) = Abrasions or physical harm resulting from purposeless activity
15. Inappropriate Activity ☐
 - (0) = Not present
 - (1) = Inappropriate activities (e.g. storing and hiding objects in inappropriate places, such as throwing clothing in wastebasket or putting empty plates in the oven; inappropriate sexual behaviour, such as inappropriate exposure)
 - (2) = Present and sufficient to require restraint
 - (3) = Present, sufficient to require restraint, and accompanied by anger or violence when restraint is used

Total Score (C) ☐

D. Aggressiveness

16. Verbal Outbursts ☐
 (0) = Not present
 (1) = Present (including unaccustomed use of foul or abusive language)
 (2) = Present and accompanied by anger
 (3) = Present, accompanied by anger, and clearly directed at other persons
17. Physical Threats and/or Violence ☐
 (0) = Not present
 (1) = Threatening behaviour
 (2) = Physical violence
 (3) = Physical violence accompanied by vehemence
18. Agitation (other than above) ☐
 (0) = Not present
 (1) = Present
 (2) = Present with emotional component
 (3) = Present with emotional and physical component
 Unspecified? _____
 Describe _____

Total Score (D) ☐

E. Diurnal Rhythm Disturbances

19. Day/Night Disturbance ☐
 (0) = Not present
 (1) = Repetitive awakenings during the night
 (2) = 50% to 75% of former sleep cycle at night
 (3) = Complete disturbance of diurnal rhythm (i.e., less than 50% of former sleep cycle at night)

F. Affective Disturbance

20. Tearfulness ☐
 (0) = Not present
 (1) = Present
 (2) = Present and accompanied by clear affective component
 (3) = Present and accompanied by affective and physical component (e.g., "wrings hands" or other gestures)
21. Depressed Mood: Other ☐
 (0) = Not present
 (1) = Present (e.g., occasional statement "I wish I were dead," without clear affective concomitants)
 (2) = Present with clear concomitants (e.g., thoughts of death)
 (3) = Present with emotional and physical concomitants (e.g., suicide gesture)
 Unspecified? _____
 Describe _____

Total Score (F) ☐

G. Anxieties and Phobias

22. Anxiety Regarding Upcoming Events (Godot Syndrome) ☐
 (0) = Not present
 (1) = Present: Repeated queries and/or other activities regarding upcoming appointments and/or events
 (2) = Present and disturbing to caregivers
 (3) = Present and intolerable to caregivers
23. Other Anxieties ☐
 (0) = Not present
 (1) = Present
 (2) = Present and disturbing to caregivers
 (3) = Present and intolerable to caregivers
 Unspecified? _____
 Describe _____

24. Fear of Being Left Alone ☐
 (0) = Not present
 (1) = Present: Vocalised fear of being alone
 (2) = Vocalised and sufficient to require specific action on part of caregiver
 (3) = Vocalised and sufficient to require patient to be accompanied at all times
25. Other Phobias ☐
 (0) = Not present
 (1) = Present
 (2) = Present and of sufficient magnitude to require specific action on part of caregiver
 (3) = Present and sufficient to prevent patient activities
 Unspecified? _____
 Describe _____

Total Score (G) ☐

Part 2 : Global Rating

With respect to the above symptoms, they are of sufficient magnitude as to be:

- (0) = Not at all troubling to the caregiver or dangerous to the patient
 (1) = Mildly troubling to the caregiver or dangerous to the patient
 (2) = Moderately troubling to the caregiver or dangerous to the patient
 (3) = Severely troubling or intolerable to the caregiver or dangerous to the patient

Score ☐

Summary Score Sheet

Part 1

- A. Paranoid and Delusional Ideation

(maximum 21)
- B. Hallucinations

(maximum 15)
- C. Activity Disturbances

(maximum 9)
- D. Aggressiveness

(maximum 9)
- E. Diurnal Rhythm Disturbances

(maximum 3)
- F. Affective Disturbance

(maximum 6)
- G. Anxieties and Phobias

(maximum 12)
- Total Score (Part 1)

(maximum 75)

Part 2

Global Rating

(0-3)

THE REVISED MEMORY AND BEHAVIOUR PROBLEM CHECKLIST

NAME: Assessment Date:

Frequency Ratings:

- 0 = never occurred
 1 = not in the past week
 2 = 1 to 2 times in the past week
 3 = 3 to 6 times in the past week
 4 = daily or more often
 DK = don't know/not applicable

Reaction of Carer Ratings:

- 0 = not at all
 1 = a little
 2 = moderately
 3 = very much
 4 = extremely
 DK = don't know/not applicable

Please answer all the questions below. Circle one number from 0-DK for both Frequency and Reaction.

	Frequency	Reaction
1 Asking the same question over and over	0 1 2 3 4 DK	0 1 2 3 4 DK
2 Trouble remembering recent events (e.g. items in the newspaper or on TV)	0 1 2 3 4 DK	0 1 2 3 4 DK
3 Trouble remembering significant past events	0 1 2 3 4 DK	0 1 2 3 4 DK
4 Losing or misplacing things	0 1 2 3 4 DK	0 1 2 3 4 DK
5 Forgetting what day it is	0 1 2 3 4 DK	0 1 2 3 4 DK
6 Starting, but not finishing things	0 1 2 3 4 DK	0 1 2 3 4 DK
7 Difficulty concentrating on a task	0 1 2 3 4 DK	0 1 2 3 4 DK
8 Destroying property	0 1 2 3 4 DK	0 1 2 3 4 DK
9 Doing things that embarrass you	0 1 2 3 4 DK	0 1 2 3 4 DK
10 Waking you or other family members up at night	0 1 2 3 4 DK	0 1 2 3 4 DK
11 Talking loudly and rapidly	0 1 2 3 4 DK	0 1 2 3 4 DK
12 Appears anxious or worried	0 1 2 3 4 DK	0 1 2 3 4 DK
13 Engaging in behaviour that is potentially dangerous to self or others	0 1 2 3 4 DK	0 1 2 3 4 DK

	Frequency	Reaction
14 Threats to hurt oneself	0 1 2 3 4 DK	0 1 2 3 4 DK
15 Threats to hurt others	0 1 2 3 4 DK	0 1 2 3 4 DK
16 Aggressive to others verbally	0 1 2 3 4 DK	0 1 2 3 4 DK
17 Appears sad or depressed	0 1 2 3 4 DK	0 1 2 3 4 DK
18 Expressing feelings of hopelessness or sadness about the future (e.g. "Nothing worthwhile ever happens", "I never do anything right")	0 1 2 3 4 DK	0 1 2 3 4 DK
19 Crying and tearfulness	0 1 2 3 4 DK	0 1 2 3 4 DK
20 Commenting about death of self or others (e.g. "Life isn't worth living", "I'd be better off dead")	0 1 2 3 4 DK	0 1 2 3 4 DK
21 Talking about feeling lonely	0 1 2 3 4 DK	0 1 2 3 4 DK
22 Comments about feeling worthless or being a burden to others	0 1 2 3 4 DK	0 1 2 3 4 DK
23 Comments about feeling life a failure, or about not having any worthwhile accomplishments in life	0 1 2 3 4 DK	0 1 2 3 4 DK
24 Arguing, irritability, and/or complaining	0 1 2 3 4 DK	0 1 2 3 4 DK

Appendix 9 – Handouts for Stage 1 of Feasibility Study

Memory Group, King's Wood Centre, Colchester - Session 1

Memory is affected by the environment.

There are different types of memory:

- **Immediate/working e.g. remembering names, introducing each other**
- **Long-term e.g. childhood events**
- **Future memory e.g. going to dentist/ birthdays**

The type of information it is can affect how we remember e.g. if it's important (such as remembering to take medicine) we're more likely to remember.

What we had for breakfast is not so important and we therefore may not remember it.

We have memory for procedures or routines e.g. knitting, driving, playing card games.

We have memories attached to our senses e.g. food smells from childhood, the smell of mother's perfume, favourite music.

Information can be spoken or seen e.g. faces, layout of building.

Stages of Memory

- **Taking in information**
- **Storing information for when it is needed**
- **Recalling information when it is needed.**

Erica Richmond, Sophie Dobson, Margaret Rosseau, Julie Scott 3.7.200

Memory Group, King's Wood Centre, Colchester - Session 2

One way to cope with memory problems is to use external memory aids.

Using a memory aid means we have to rely less on our memory.

These aids also help to maintain the memory which we have.

Examples of external memory aids are:

- calendar

- newspaper to remember the date

- writing lists of things to do

- birthday book

- diary or filofax

- wipe clean memo board

- pill reminder box or keep pills in a certain place

- notepad by the telephone to write down messages

- pre-set telephone numbers

Having a regular routine and being organised can also reduce the strain on memory.

At first it may be difficult to get used to using new memory aids.

Reminders may be needed initially to actually use the aid. However, after a while it should become easier and more natural.

People find that some memory aids suit them and some do not. It is important to use a memory aid which suits you.

Most people find that using a combination of memory aids is the best way of combating memory problems.

Memory Group, King's Wood Centre, Colchester

Session 3

Techniques which use visual or verbal reinforcement can help in remembering things

- Try to put a picture to names
- Use distinctive features to help remember people
- Use rhyme, for example, 'Thirty days hath September...'

How can we help people get information into memory more efficiently?

- Make information relevant
- Simplify information and written instructions
- Divide information into small chunks
- Give chunks one at a time
- Break down activities into small parts
- Do tasks together - to remind someone how to do the task
- Ensure information has been understood by asking them to repeat it to you.
- Ask them, in a little while, what information was given:- repetition and practice helps memory.

Memory Group – King's Wood Centre – Session 4

Changing the home environment can help our memory.

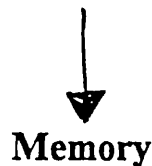
Examples of this are: -

- ◆ **have a home for everything, everything in its home**
- ◆ **arrange clothes in order in the drawers**
- ◆ **use clear plastic for storing things**
- ◆ **have things that are used most often in an easily accessible place**
- ◆ **have a newspaper delivered daily to provide prompts – day of the week, not forgetting to dispose of out of date papers**
- ◆ **keep a “memory book”, including photographs and mementos of important events**
- ◆ **put labels on draws and doors to rooms**
- ◆ **paint the toilet door a different colour from the others**
- ◆ **use a Medipak to help remember to take medication at the right time of day**
- ◆ **attach things, such as keys, spectacles to yourself with a cord or key fob**
- ◆ **place a STOP sign at the front door**
- ◆ **use smells to remind you of pleasant memories**
- ◆ **play favourite music**
- ◆ **seek out clues in the environment to inform you of season, time of day etc**
- ◆ **stick to a set routine**

§. **Taking in Information – How We Feel Affects our Memory**

Information is attended to via one of our senses (e.g. hearing/seeing things). When we are trying to remember something, we need to attend to it, so it can be placed in our Immediate Memory. From here, certain pieces of information will be passed on to be stored more permanently in our memory.

Things which we attend to or concentrate on



When we are able to fully attend to or concentrate on information, we are more likely to remember it.

Things which help us to take in information:

- Being focused on a topic
- Hearing/seeing information clearly
- Feeling relaxed
- Not being preoccupied with things on your mind
- Taking in information which is meaningful
- Picking out the important bits to remember – lightening the load
- Having a good night's sleep – feeling refreshed
- Being aware of times of the day when you feel more alert

Things which hinder us when taking in information:

- Feeling worried/anxious
- Being distracted by other things – preoccupied mind
- Feeling down/fed-up/upset
- Feeling bored
- Feeling hopeless e.g. 'What's the point, I'll only forget it later?'
- Being worried about what others will think e.g. 'that I'm stupid'
- Doing too many things at once
- Feeling tired

It is important to remember that everyone forget things sometimes. People are more likely to focus on times when they forget, when others may not actually notice. It is natural to forget some things.

Ways to help us to minimise times when we feel anxious or worried:

Distraction

Do something you enjoy e.g. knitting, chat about something else, go for a walk, listen to the radio or watch the TV.

Take some time to have a good look at a picture. Look at it in detail. This will give your mind a rest for a short while.

Breathing Exercises

Take a deep breath in and then take two breaths out. Repeat.

Muscular Relaxation

This works by tensing muscles for five seconds and releasing them – noticing the difference between feeling tense and relaxed. For example, clench fists, screw up face, hunch shoulders, bend toes and feet upwards. This exercise can also help you to identify when you are feeling tense in parts of your body.

Hope this is clear. Please ask if anything isn't. Look forward to seeing you on Monday!

Erica Richmond, Sophie Doswell, Julie Scott & Margaret Rossario

Memory Group, King's Wood Centre, Colchester

Session 6

How to cope with forgetting

When we forget things in social situations we may feel frustrated, embarrassed or stupid.

Things that may help are;

- 1) Writing it down when you do remember**
- 2) Thinking of other information that is related to what you have forgotten**
- 2) Asking other people to say more – get clues**
- 3) Trying not to worry**
- 4) Asking your spouse to help fill in the gaps**
- 5) Using the direct approach. Saying to people 'My memory is terrible.'**

It's also important to remind ourselves of our positive points e.g. having a good sense of humour, being generous, being helpful.

Julie Scott, Erica Richmond, Margaret Rossario and Sophie Doswell.

8.08.2000

Summary of what we covered in Memory Groups, King's Wood Centre, Colchester

Week 1

We discussed the fact that there are different types of memory.

These include:

- immediate memory, (e.g. remembering peoples' names when we have just been introduced to them).
- long-term memory (e.g. childhood events).
- future memory (e.g. appointments).

Week 2

We looked at memory aids. For example:

- calendars
- looking at newspapers to remember dates.

Week 3

We looked at other techniques we can use to help us remember things. For example:

- using rhymes
- trying to put a picture to names.

Week 4

We discussed how changing the environment can help our memory.

For example:

- having a home for everything
- putting labels on drawers

Week 5

We looked at how our memory can be affected by how we are feeling. For example, we are more likely to remember something if the topic is important to us or we feel relaxed. We are less likely to remember if we feel worried or anxious.

Week 6

We looked at how to cope with forgetting. For example:

- writing things down
- trying to get 'clues' from people.

Week 7

This was an open session.

Sophie Doswell, Margaret Rosseau, Erica Richmond, Julie Scott 17.8.00

Appendix 10 – Handouts for Stage 2 of Feasibility Study

North East Mental Health Partnership NHS Trust - Memory Course

Session 1 - Models of Memory and Memory Processes

There are different types of memory:

- **Memory for facts (e.g. the capital of Paris)**
- **Memory for personal experiences (e.g. what you had for breakfast today)**
- **Memory for skills and procedures (e.g. riding a bicycle)**
- **Memory using different senses (e.g. memory for the smell of someone's perfume)**
- **Immediate/ working memory (e.g. remembering a phone number)**
- **Long-term memory (e.g. where you were born)**
- **Prospective memory (e.g. the date of someone's birthday)**

There are 3 stages in remembering:

- **Taking in information**
- **Storing information**
- **Recalling information when it is needed**

Points to consider:

- **We are more likely to remember important information**
- **We all forget at times**

North Essex Mental Health Partnership NHS Trust

Session 2 – Memory Aids (Handout for partners)

Memory Aids can be *internal* or *external*.

e.g. an *internal* memory aid is repeating information.

***External* aids may work best.**

Examples of *external* aids are:

- **Newspaper (for the date)**
- **Diary/Calendar (to remember the date and appointments)**
- **Notepad by telephone**
- **Post-it notes**
- **Memo board**
- **Pill reminder box**
- **Making lists**
- **Photo album**
- **Memory Book**

External Aids also rely on internal strategies. e.g. you need to remember to write appointments on and check a calendar.

Points to consider:

- **There is no evidence to suggest using memory aids prevents people's memory from improving**
- **The memory aid should be in an obvious place**
- **It is probably best for your partner to expand the use of memory aids he/she is already using rather than use new ones**
- **You should regularly remind your partner to use the memory aid at first. You may be able to gradually decrease the reminders as time goes on.**
- **People often use a combination of memory aids.**

North Essex Mental Health Partnership NHS Trust

Memory Courses

Session 3 – Taking In Information

There are different things we can do to help us remember things better.

Some of these are:

- Make sure you can see and hear the information alright**
- Pay attention to what you are trying to remember**
- Spend time trying to remember something**
- Try to remember one piece of information at a time**
- Try to remember just the important information e.g. the main part of a message.**
- Use several techniques to try and remember information e.g. read something and say it out loud**
- Make an association with what you are trying to remember and information already stored in your memory (e.g. the name of a person you have just met with the name of a famous person).**
- Go through the alphabet to try and recall the first letter (and hopefully then the whole name) of something**
- Do a task with someone**
- Keep practising – keep going back to the information you are trying to remember.**

North Essex Mental Health NHS Trust – Memory Course

Session 4 – Adapting the Environment

Changing the home environment can help our memory

Examples of this are

- Putting things that are used most often in a certain place.
- Putting two items together – the one you need to remember to use with an item you use every day.
- Putting items in unusual places.
- Arranging clothes in drawers in an order that works best for you.
- Labels on jars or other items.
- Colour coding items.
- Leaving an empty carton of an item that needs to be replaced somewhere obvious.
- Arranging items according to how frequently they are used.

Points to consider

- Placing items in a certain place may be helpful (e.g. a diary by a chair we use a lot). However, when items have been somewhere for a while we get used to them being there and may no longer notice them.
- Having a regular routine can help.

North Essex Mental Health Partnership NHS Trust – Memory
Course

Session 5 – How feelings affect memory

The way we feel affects how we remember things

What makes us remember things less well?

- **When your mind is on other things**
- **Thinking about the past and future rather than now**
- **Your mood – feeling worried or depressed**

What can help us change these feelings?

- **Stopping what you are doing for a while**
- **Taking time out**
- **Talking about your feelings**
- **Distracting yourselves – watching T.V., hobbies, pets, thinking of something pleasant**
- **Not thinking in ‘all or nothing’ terms.**
- **Trying to think about some positive things have happened recently**
- **Identifying resources you have**

North Essex Mental Health Partnership NHS Trust – Memory Course

Session 6 – Coping in Social Situations

People may have difficulty in social situations because they cannot remember something e.g. the name of a person.

What can help?

- **Keep the conversation going and try to pick up clues**
- **Explain to the person that you are unable to place him or her**
- **Try to relax and stay calm**
- **Pick up clues from others**

Positive aspects about yourself

It is important to think about all the characteristics you have that other people say they like

North Essex Mental Health Partnership NHS Trust

Memory Course

Session 7 – Summary of Sessions

What we have covered in the sessions:

Week 1

The different types of memory e.g. memory for facts, memory for things from a long time ago, memory for remembering a telephone number for a few minutes.

The 3 stages in memory – taking in information, storing information and retrieving information

Week 2

Types of Memory Aids e.g. calendars, newspapers, memo boards.

Week 3

Ways we can remember information better e.g. spending time trying to remember it, repeating information

Week 4

Ways of changing the environment to help memory. e.g. keeping things in a certain place, arranging clothes in order in drawers

Week 5

How feelings affect memory. Feeling worried or depressed will make memory worse. We can do things to help us feel better e.g. talking to others, hobbies

Week 6

How to cope in social situations. If we cannot remember someone's name we can keep the conversation going and pick up cues or being direct and saying you are unable to place them.

Appendix 11 - Schedule of Questions for pre, post and follow-up sessions

Pre-intervention

What are your goals relating to your partner's memory/

Post intervention

1. Were your individual goals addressed by the intervention?
2. Are there any memory strategies or techniques you remember from the course?
3. Were you/ were you not using these prior to the course?
4. Are you currently implementing any of these as a result of the course?

Follow-up sessions

If previously state individual goals were met by the course ask if this is still the case.

Ask questions 2 and 4 above.